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EDITORIAL

Safeguarding Personalised, Individualised and Family Support Services

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“Long before you can safeguard anything, you need to know what it is you want to safeguard and why it matters to safeguard it”. Michael Kendrick. 2004.

This edition of CRUcial Times is dedicated to deepening our understanding of the value of personalised service approaches created by individuals with disabilities, families and allies. It seeks to celebrate these initiatives, to recognise and to safeguard these forms of personalised support services.

Historically, human services have operated with high levels of control over the lives of individuals with disabilities, using a form of service that has a ‘one size fits all’ approach and taking little or no account of the needs and aspirations of the individual person. In addition, services have become the dominant response to meeting the support needs of people with disabilities and as a consequence the natural development of informal support arrangements based on freely-given relationships has been sidelined.

Rejecting the dominant forms of service provision, many people with disabilities and their families have found ways to ensure that their personal authority and individual sovereignty hold a central importance in their own service arrangements. This is based on the important belief that people with disabilities can and should have autonomy over their lives. This is reflected in their support arrangements and this autonomy needs to be recognised and safeguarded.

The notion of ‘safeguarding’ does not mean increased safety measures and controls or avoiding creativity or innovation. Safeguarding refers to a range of actions that are based on a conscious awareness of the vulnerabilities of individuals. Safeguards minimise the likelihood that the interests of the service or the system will overshadow the interests of the individual or that the focus of the service shifts away from the most vulnerable party. Personalised approaches always hold a vision of social inclusion. Safeguarding is about protecting this vision and fostering conditions that enable people to live out individual dreams, desires and hopes in the midst of a complex bureaucratic service system.

This edition asks the questions: What is the range of actions that enable people to live out their individual dreams, desires, hopes and vision: and how, in the face of complex bureaucracies, do personalised responses maintain the focus on the person with disabilities?

Part of the answer is to encourage an active commitment within the bureaucratic system to the development of personalised support arrangements and services so that:

- decision-making occurs at an individual level or at as local a level as possible,
- people who are employed in leadership roles within the bureaucracy have good knowledge of the experiences and needs of people with disabilities;
- pilot projects and authentic innovation are encouraged; and
- relationships are developed with people who are good at negotiating and providing better partnerships between the formal system and the individual and family.

There are many areas of service arrangements over which people with disabilities or families can assume authority, although not all people will want control

CRU’s MISSION STATEMENT

- To challenge ideas and practices which limit the lives of people with disabilities.
- To inspire and encourage individuals and organisations to pursue better lives for people with disabilities.

over all aspects of their service arrangements. These could include:

- holding the values and vision that define what a meaningful life might look like and what a good service is for them;
- setting priorities in terms of which needs are the most pressing;
- choosing the identity and role of those involved, both in paid and unpaid positions;
- deciding how and when support is provided;
- shaping the parameters of support arrangements;
- defining how much formality is in the service arrangement, such as the forms that are used and the communication channels; and
- controlling the financial arrangements.

These aspects illustrate a type of governance where the individual or the family and the service provider engage in a partnership. The individual or the family assumes an explicit, central role in authoritative decision-making and the service maintains reasonable accountability requirements in the least bureaucratic manner.

Ultimately striving for individualisation is not about individualism, it is not about doing it alone, but it is about recognising our common humanity and the need to support each other. Initiating, forming and supporting freely-given relationships in the lives of people with disabilities are the most potent safeguards for individualised lifestyles. Even in this time of technocratic management there is evidence that personalised approaches are not only possible, but are also providing real opportunity for people with disabilities to live ordinary lives, as part of the community and surrounded by ordinary networks of people. With the commitment of people with disabilities, families, friends, allies, service workers and management committees to keeping the person at the centre of the focus, ensuring grassroots governance, shifting societal attitudes and building a more certain future, people from across Queensland are continuing to demonstrate the strength of personalised approaches. In essence, safeguarding personalised approaches is a safeguard for the future.

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From the President

Mike Duggan

In Queensland small service agencies run by people with disabilities or families are viewed as a valued mode of providing support services. These types of service agencies provide families and individuals with some real choices.

At a recent gathering of people involved with small family-governed or user-governed services in South East Queensland a number of essential characteristics common to this type of service were identified. These are:

- The service exists for the people served. Its committee comprises the people who use the service, family members and their close allies. The interests of the service and service users are shared and mutually-sustaining.
- The provision of support arrangements is flexible, creative and innovative. Support arrangements are designed around individual needs and are respectful of individual lifestyles. The people who use the service are well-known, as are their needs and wants. The service is directly accountable to the people who use the service.
- Support arrangements are built on the contributions of informal supports such as family, friends and community connections. The creation of personal relationships and opportunities for these is fully explored and encouraged.
- The service maintains a low profile in the person’s life. But is aware of vulnerabilities and is conscientious in building safeguards into the person’s support arrangements.
- There is an overall transparency to the way the service is conducted. The general community and individuals can clearly see how the service agency does its work. The service is clear and articulate about its purview.

However, there is a perception that small services such as these are expensive, ‘Rolls Royce’ services, but this could not be further from the truth. Small services, dollar for dollar, are very economical as most of the funds are directed to service users and are not absorbed by administration or other non-support costs.

Small services are, by their very nature, in a better position to develop long term, close relationships with the people to whom they provide support. By virtue of their small size, they are more easily able to ensure that people with disabilities and their family are at the heart of their work. For example, they have the time it takes to understand the person and her or his needs and can work on a one-to-one basis to establish community connections and informal types of support that enrich life and reduce the person’s reliance on formal support systems.

Small family-governed or user-governed services are more easily influenced by the people they serve. The services work alongside the person in partnership, taking direction from that person or family. Forward-planning is undertaken, based on knowing the person and his or her needs and aspirations and time can be taken to plan for these needs. This way of operating lessens the likelihood of crises developing.

Small service agencies provided by and for people with disabilities and families provide opportunities to express and explore individual identities, build relationships and contribute to the social exchange processes that establish people as strong members in communities. Those members of small family-governed and user-governed services who recently gathered did so in order to identify the most important characteristics of the small services that they have created and to find ways of safeguarding and ensuring their continued existence because they recognise how important it is to be able to shape their own support arrangements and lifestyles.

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Personalised Services and Support Arrangements:
What Has Happened In Queensland

Jan Dyke *has a long history of being a friend, ally and advocate in the lives of people with disabilities and is passionate in her commitment to working towards making a real and sustainable difference in their lives. Here Jan explores some of the historical background and fundamental beliefs that have shaped the development of personalised support services in Queenslanl. Jan acknowledges this paper could only be written because of her long involvement with such luminaries as Joan Hailstone, Michael Kendrick, Margaret Ward and the people involved with Speaking Up For You and others.*

Many people have been struggling for a very long time to make a real difference in the lives of people with disabilities. From a Queensland perspective, the 1980s is often identified as a decade in which a significant turning point was reached in this struggle. What happened in the 80s to create this turning point? For many people, this period was accompanied by a change in thinking about where people with disabilities belong, which in turn raised questions about the dominant approach of stereotyped group arrangements. A new approach to support services began to emerge. Instead of removing the person to a life apart, manufactured by the services, support arrangements were provided where and when they were needed.

While many people seemed to agree with this new approach, entrenched values and attitudes did not facilitate change. What resulted for many people was more of the same style of services, only now cloaked in different language, set in smaller groups and with improved physical conditions. Yet a bed in a house was still not a home and fundamentally the same dominant service model remained and the system juggernaut rolled on.

At this point in time some people with disabilities and some family members had the courage and the leadership to venture into the unknown and to begin to imagine new alternatives, often seeking allies along the way with the same vision. This vision was to achieve the deceptively simple aim of people with disabilities living valued lives, comparable to those on offer to most other citizens. Together they created personalised services and support arrangements, which were flexible and responsive to people's needs and were different for each person.

This new way of thinking focussed on a real life in the community, relationships, interdependence and participating and contributing to everyday life. It was also personalised, relating to the person's needs and aspirations, which meant a shift in the power structure, with the person and the people closest to him or her influencing how life would be played out. This approach questioned where and how services fitted with life and acknowledged that there was much more to a good life than just having funding or a service.

These personalised services and support arrangements were marked by a strong commitment to an ethical framework with guiding values and principles that determine how life and its relationships are played out. This values framework is outlined in the following statements.

People with disabilities belong in community life and are entitled to live a valued lifestyle based on the same rights, relationships, expectations and opportunities as other citizens.

This means in practice that each person is well-known and well-treated with dignity and respect shown in everyday interactions, feelings and language. The vulnerability of the person is minimised and that person receives responsive, flexible and creative personalised support. A person's home is treated as a private sanctuary where life is played out in a unique and personalised way based on who lives there and how she or he wants their personal or family culture and their personal preferences honoured.

Life looks different for each person and takes up the moving feast of opportunities, experiences, relationships, decision-making, challenges and change and is not unnaturally restricted to segregated settings. Each person has a range of lifestyle activities and friendships and is supported to be included in the fabric of their neighbourhood and local community, to have real connections and relationships and to participate and contribute in everyday life. Personalised support arrangements are highly relevant to what the person needs the most and the service does all it can to support the personal or family vision of life with the person.

People have a natural authority to influence the direction of their own life, as do their family members and significant others when they have remained faithful and committed to the person's well-being.

This means in practice that each person influences how life is played out. Therefore the formal service system is acknowledged as part of the solution, with family, friends and significant others playing a legitimate and valued role.

These people are supported and encouraged to be in the person's life and to imagine and create better options with the person. The person is supported to connect with, visit, celebrate with and provide hospitality to people who form his or her natural network.

The decisions about how life is to be played out and the assistance needed are made as close as possible to the person with the people and the service working together with mutual respect, openness and trust. Planning is tailored around a personal vision for life, not around what a service can offer and is done in the spirit of 'this is this person's life, not our life'. The people involved can refuse options or negotiate on matters of concern. Everyone is clear what is personal or family business and what is service business. The person's daily life should not be consumed by bureaucracy, standardised responses, regulations or processes and the service acts as the buffer against such requirements.

Collective oversight of governance of the service is vested in the people who use the service, family or significant others who are closest to them.

This means in practice that the person, their family or significant others create and share the collective values, vision and understanding of a personalised service. They are involved in decision-making about major directions and policy of the organisation or take on governance roles on the organisation's board. The people strive for continuous improvement and are prepared to reflect on how the service goes about its work, having mechanisms that feed in information from the people who are being supported.

All people involved acknowledge that formal services are not guaranteed and can lose their way and increase the vulnerability of the person with disabilities.

This means in practice that appraisal of life happens routinely from the personal perspective of those involved and within the established framework of values and beliefs. Safeguards are put in place to protect the person in daily life and consideration is given to planning for the future, including how the person with disabilities will be supported when family and other informal supports may no longer be in the person's life.

The service has a commitment to remaining small, with a capped number of people it can support and usually only with a hierarchy of a coordinator and direct support workers. The sustainability of the service is based on renewing its vision and leadership over time and through successive generations.

Even with a sound values framework such as this, personalised support services are not perfect; they share all the usual shortcomings and the highs and lows of everyday life. They also involve huge commitment and hard work. However, people with disabilities who are supported in these ways agree, they would much rather put their energies into creating this positive model of personalised support service, rather than waste their energies on trying to fix the traditional model of service.

In the 1980s and 90s this vision and support for these small personalised support services grew, but today this support is diminishing. These small services have not had the public recognition they deserve and although they have survived, they have not had a broad impact on dominant ideology and practice.

The strength and leadership of the people involved has been the major force behind the development, survival and co-existence of personalised support services alongside the massive formal system. Wrongly labelled as either 'Rolls Royce' services or quaint aberrations on the fringe, new personalised services are difficult to establish and those that exist are subjected to many threats. This has meant that people with disabilities, their families, advocates and allies have to work hard against the dominant service paradigm and the shift in government policy and practice back to stereotyped, grouped arrangements for people with disabilities. So while some might argue that the Community Living Movement is dead, it is very much alive, and working hard supporting personalised approaches. However, movements need renewal. We need to ensure that the future of this movement continues to be sustained by the efforts of people who believe in rebuilding and safeguarding personalised support services as an important avenue for people with disabilities to lead good and ordinary lives, comparable to lives of other citizens, played out in the same valued ways and places.

We may know
how far we have come
by how far we have to go
But we can never turn back
because we have tasted the future
We have seen if only for some moments
in the faces of people
feeling dignity
power
community
the vision
of a future just society.

(Kahn, S. 1982, Organising: A Guide for Grass Roots Leaders, New York: McGraw-Hill)

Ten Guidelines for Family Governance of Services

We invited ***Margaret Ward*** *to share the principles and guidelines she has found helpful in her role as both a parent and as a board member of a small family-governed service.*

It is nearly seven years since my eldest daughter left the family home to move into her own home. This was when I really began to understand my long-term role as a family member and the art of family governance.

Even before my daughter moved into her own home and I had joined the committee of Homes West Association Incorporated, a small family-governed support service in Brisbane, I practised and developed the art of family governance, not only as an individual but also from the perspective of a board member of a service. Based on these experiences I offer the following guidelines, acknowledging all those who have guided and supported me along the way.

1. **Understand your natural authority as a family member**
   Michael Kendrick's short article *The Natural Authority of Families (*CRUcial Times, July 1996) says it all. (I keep a copy on my fridge.)
   Be clear about your role as a family member and as the person with the most information and greatest commitment to the person with the disability. If you are not clear, no-one else will be clear. A family-governed service means just that – **you** have to govern. This takes time and commitment. You may have to give something up and acknowledge that you cannot have everything. However, this does not have to be a difficult decision. The time and effort required is positive and pleasurable when you balance the experience of successful family governance against the frustration and waste of energy trying to change large, unresponsive service organisations.

2. **Know where you are going**
   Take the time to reflect on and be clear about your beliefs, assumptions and goals. Change is a constant, don't fight it – be ready to change and be positive and excited by the challenge. Recognise this is a journey not the destination. Know what is and what is not negotiable in your vision for the future of your family member.

3. **Defend your family business and define the service business**
   Keep your family business in your control. Family business means protecting the history, culture and rituals of your family while setting the vision and defining the quality, style and quantity of the service you want. Be clear about the boundaries of family and the boundaries of service provision and know how to recognise and respond to breaches.

4. **Solve problems quickly, locally and creatively.**
   There will always be problems. Problems tend to grow if they are not dealt with promptly. If possible, seek solutions as close to the person and as quickly as possible. Try to have a couple of people (other than you) looking out for potential problems. With regular meetings, ready availability by phone and needs attended to promptly, the potential for problems becoming serious are more likely to be avoided.

5. **Plan, plan, plan and be ready for spontaneous opportunities**
   Life for people with disabilities can easily become routine, predictable and boring. You cannot afford to take the comfortable option – you will need to plan new opportunities, holidays, outings, visits and guests. Sometimes spontaneous things happen which throws out the plans! Be flexible and creative and take advantage of these spontaneous opportunities. Remain within the sphere of influence; the further away from the decision-making you are, the less likely it is that spontaneous opportunities will be taken up.

6. **Be ready for things to go wrong – safeguard, safeguard, safeguard**
   Things do go wrong. Mistakes are made and people get hurt. People with disabilities are the most vulnerable and are most likely to suffer. It is therefore important to safeguard the person in three ways:

   Promote: speak well of the person and ensure both staff and the person are well presented.
   Protect: try to ensure secure housing tenure, excellent medical care, well trained staff, good equipment and have the capacity to dismiss unsuitable staff immediately.
   Redress: put in the extra time and effort to ameliorate any negative experiences by the person; analyse why a negative event happened; spend time with staff for critical reflection to avoid a reoccurrence.

7. **Develop the skills you need.**
You need to have robust values and beliefs, based on a theoretical framework (Social Role Valorisation theory serves me and Homes West the best). Develop the skills that make life easier: budgeting; computer skills; driving a car; using a mobile phone; running a meeting; negotiating skills; asking for help; keeping good records. Many of these skills are developed in the process of raising a family.

8. **Work with a spirit of respectful relationship**
- Treat people respectfully and expect people to do their best (people will do best when they are treated respectfully).
- Acknowledge the ideas and skills of others:
- Acknowledge that others have much to contribute. Families do not need to know how to do everything – each person has something to contribute to the person's life.
- Give the power to the person who can solve the problem in the best and the quickest way.
- When there is opportunity to learn, share the lessons and learn together.
- Foster a culture in which honest mistakes are forgiven and in which people can share their ideas and skills and are morel likely to own the solutions.

9. **Protect yourself from bureaucracy**
While bureaucracies may have little understanding of family governance, accountability and reporting are important and must be done. However, protect yourself from these tasks if they cut across your important role as a family member. Bureaucratic practices are often based on a 'deficit model', which emphasises the negative aspects of the person with disabilities – what the person cannot do rather than what the person can do – and emphasises families as victims. Services can protect the person with disabilities and the family from this difficult process.

Beware of allowing bureaucratic practices to dominate how you do things. Think 90% creativity, values and commonsense action and 10% technocracy. Keeping services small, friendly and manageable – a group of 8 to 12 family members can sit around a table and solve most problems.

10. **Know you are mortal**
Recognise, acknowledge and plan for that certainty of life – death. Our most important task as family members is to make ourselves redundant over time and to die knowing that others are ready, willing and prepared to assume our role. This is not about handing over to a service but finding other committed people who will take our place to govern. It means handing over responsibility to other family members or friends – small tasks at first, then greater responsibilities as the people become more knowledgeable and responsible themselves. This process needs to happen at both the family and the service level and we need to make it happen as it will not happen naturally; it will need to become part of everything that we do. In the end, this is about acting generously and handing over the most important job in our lives to those who also love our sons and daughters, sisters or brothers.

These are important matters to me and my family and I offer these guidelines in the hope that they might be helpful for others who are looking for ways of asserting their natural authority as families and ways of safeguarding small family-governed services.

Individual Governance – A personal perspective

Bill Garsden *considers some important personal issues about self-managing his own support arrangements. Bill acquired his disability twenty-seven years ago and has lived at home with support for twenty-four years. He hopes his life experiences are of assistance.*

I have been directing my own support arrangements for about fifteen years. Well, in truth, it has very much been a joint effort with my wife, Lee. This article will centre on our combined experiences. Initially, for about seven years, I used a service provider. Experience gleaned during those seven years gave us the confidence to direct our own support arrangements.

After fifteen years, I can confidently say that the advantages of managing our own support service definitely outweigh the disadvantages. Initially, the reason for changing was financial. The service provider's costs had increased considerably, mostly incurred by management procedures.

It definitely takes more effort to direct my own support service. I find, by sharing the work load with Lee, it does work out much better for us both. I recommend you be strategic about how you run your own service; for example, do not overemphasise particular aspects of your life, such as the medical needs or overburden yourself with administrative detail – it is essential that you maintain the appropriate level of focus on various aspects of your support. Always remember that the most important aspect of the service is to ensure that you are supported to live as full a life as you can.
Determine what your worst fears are and try to have procedures in place to deal with them. For example, what do you do if nobody turns up for work, or you can not find staff? Is it worth having an emergency arrangement with a local service provider to fill in gaps? We do not have an emergency arrangement, but we have often considered one.

It is important to be clear about your expectations of staff and to give them clear instruction and feedback. Be clear about your privacy, so that your personal details are not disclosed to others. Work out ways to manage your security, both personal and financial. Determine secure ways for staff to enter and leave your home and, if possible, never disclose your private financial details (especially bank PIN numbers). My needs are known and well-defined and therefore can be managed so that they minimise the impact on my dearest. But there will always be some impact. It is crucial for us to recognise this and to negotiate these matters to maximise the independence of each of us.

I find the most stressful time is when hiring and training a new worker. If new staff workers are quick learners, self starters and reliable, the arrangement is beneficial for everyone. However, this does not always happen; some workers are there for the long term, while others are there until something better comes along!

It is important to know and fulfil your obligations as an employer and deal with situations as they arise with clear communication. However, it is important to acknowledge that sometimes it will not be possible to maintain the typical professional boundaries usually associated with being an employer or employee and this can be difficult for all concerned. Our maxim has always been to treat all workers with respect and to hope that this will be returned: it usually is. With staff regularly at our home (and bedroom), it is critical that privacy, dignity, personal space, time-out and balance be maintained for me, Lee and my staff. We all have needs. Recognise your needs and direct support arrangements to suit them. It is also critical to adequately support staff and to recognise their needs. Some are universal needs, others are personal needs.

Determine where you think you have skills and where you don't. In the 'don't' column, assess where you need support or training to allow you to undertake your desired tasks and when to pass tasks on to others. Two examples: You may be inexperienced in interview techniques. A solution could be to ask someone with those skills to help and train you until you feel confident. Lee and I do all interviews together and play different roles. Book-keeping: Is it worth your efforts to do your own books of accounts, or should you employ a bookkeeper? Many people opt for the latter. Lee does ours.

One important aspect is of taking on the role of an employer and to understand the responsibilities that this entails. In my experience, the most time is taken up in these three areas of responsibility;

- ***Recruitment*** – Advertisements used by others can be modified for your purposes; answering phones (potentially very time-consuming) can be managed by using an answering machine; we do interviews together and schedule them to suit our needs.

- ***Training*** – Lee does initial training, then does buddy shifts to quickly get new staff up to speed; I then do the more detailed, long-term personal training.

- ***Administration*** (timesheets, staff records, wages, banking) – we use a simple ruled exercise book for a time book; ensure you get copies of genuine ID such as a drivers licence, blue cards, police reports (if you require one), training certificates, plus contact details and next of kin and other records such as first aid certificates, vaccination records etc. Lee calculates wages, related staff payments and taxation records and we use MYOB accounting software, direct deposits and Internet banking.

The main issue to us is reliability. I want to know that I have a reliable staff platform from which I can plan my life. My day goes downhill if nobody turns up for work. Lee and I work on procedures to cover that. I try to have enough staff to have someone to cover any such gaps. Consequently, I do not like having any one worker doing the majority of shifts. I also try to keep ex-staff on an emergency list. I am fortunate that in a real emergency, Lee can usually fill in.

The list for directing your own support arrangements may appear long and daunting, but we have found that, with team work, planning and a dash of reality, we managed the transition from a service provider to managing our own service arrangements. The rewards are many: control over our own lives, control over staff selection, more reliable staff, less staff turnover, better staff relations, staff loyalty, better work practices, less personal stress, less marital and family stress, more predictability and a better life. We have tried both approaches and directing our own support arrangements is highly recommended – it is cheaper and has better outcomes. Everyone should have this option.

What gets in the way of person-centredness in services?

Adrienne McGhee *works for an organisation which recently supported approximately fifty people to move from an institutional setting to live in their own homes in the community. She discusses some of the challenges involved in ensuring support is person-centred.*

Person-centredness is a framework that many services espouse when supporting people with disabilities. Many of us who work in these services talk passionately about person-centredness and how we can ensure that the individual people we support are the central focus of our efforts. Why is it then that so many individuals continue to live lives that are confined by a service context and are excluded from the richness of life that is sought by people in the general community?

Disability service organisations are funded to support individuals to construct ‘typical’ lives. Services, however, must also negotiate a maze of obligations and limitations that are not directly related to the wellbeing of the person. Consequently there are multiple interacting factors that interfere with the best intentions of person-centred practice. At the risk of simplifying a complex reality, I have divided these interacting factors (of which only a few can be outlined) into two themes: material limitations; and the prevailing mindset that exists within many services.

Few of the material factors that influence service provision are unknown to anyone involved in the lives of people with disabilities. To many families exhausted by the struggle to build meaningful lives for a person through services, demands of ‘accountability’ by services may seem like hollow excuses for failing to do what services are funded to do. Perhaps they are. Yet, from a service perspective, the existence of a service is contingent on meeting accountability requirements. Most people would be aware of a current example of a material demand on services – DSQ’s (Disability Services Queensland) new quality assurance system which requires services to pursue and achieve accreditation by 2008. Even with the voluminous material and the guarantees of support provided by DSQ, small services (which cannot afford to hire additional personnel to undertake the project) can feel compelled to take time away from people who receive their services to ensure that the service can meet DSQ requirements.

Resources that are provided by government directly influence the priorities of service personnel. Funding levels directly affect our ability to sustain focused, personalised and dignified support to people. Research into human service systems acknowledges that person-centred approaches involve considerably more time than do systematised approaches; people living in institution-like settings with highly-regulated processes can exist with minimal staff. It takes time to get to know people well and gain their trust, to genuinely explore their values and preferences and to seek out opportunities for their expression, to nourish relationships and to build confidence, skills and a sense of personal autonomy, all of which are implied in a person-centred context.

While material factors play a major role in compromising person-centred practice, the prevailing mindset within most services provides one of the most stubborn barriers to establishing authentic person-centred human services. Our own pre-conceived assumptions about what is best for the people we support is one such barrier. Often the starting point for service delivery is not the person; it is our own thinking, personal and professional expectations and frameworks. In such cases we fail to protect the uniqueness of people and apply our organisational systems and strategies to clients. We mistakenly adopt the adjective ‘person-centred’ and justify the use of the word because we are no longer providing a service for people living in an institution but for people living in their own homes with their own staff in a nearby community.

Furthermore, for person-centredness to be entrenched in our organisational responses to people, it has to be the mindset of all staff. In a time of chronic staff shortages, we find it difficult to find workers whose values are congruent with our frameworks and whose skills, attitudes and availability meet the needs of the people we support. The amount of training, team work and individual mentoring required to promote the adoption of new frameworks is therefore huge.

Additionally, time management principles require that we devise effective systems to streamline non-people-related tasks. So, while working alongside people in unique and unhurried ways, we must simultaneously develop and maintain efficient work practices. Ironically, if we are not conscious about the processes we are using and the mindsets we are adopting in order to create and maintain these systems, our overall thinking can become hijacked by managerialist values such as targets and outcomes, processes and systems rather than working patiently with people in the myriad of life's complexities.

Therefore, while we have genuine commitments to working with people in ways that support them to live good lives of their choosing we struggle to manage the challenges brought by formal service provision. We acknowledge that this is a struggle, but we cannot allow these challenges to stand in the way of person-centredness practice. The resolution of that struggle lies in remaining faithful to our vision for people with disabilities to share in the richness of experiencing an ordinary life in community. My hope is that, through a cohesive community of individuals with disabilities, their families and allies, services and government, we will openly, respectfully and constructively address the many tensions inherent in providing authentically person-centred services and do everything we can to clarify, facilitate and protect a deep sense of person-centredness in service provision, policy making, funding arrangements and community involvement.

Reflections from a Grumpy Old Man

Ric Thompson, *manager of Inclusion Works in Townsville, reflects on what we can learn from history about protecting and maintaining community and organisational values.*

A group of well-known men first raised my consciousness about my own present state of mind. It was the group of men who were interviewed about their woes in the BBC production *Grumpy Old Men* recently shown on ABC television. It was true that I had all the classic symptoms of a grumpy old man – I was within the right age group and like a member of a secret sect shared my dislike for many modern trends. But why and how had I become one?

I love my job in a small community organisation that supports people to link into their specific interest areas in the local community. I wake each morning with a zest for life and a passion for the challenges ahead. But something had happened – I had become suspicious, analytical, cynical and critical. I was keen to find out why. With some knowledge of human service systems analysis I surveyed my diary to identify those moments that may have fuelled my grumpiness. It didn't take long, for my body tensed as I realised the cause – 'meetings'. Not just any meetings – the meetings which had fuelled my condition all have a common characteristic.

This characteristic is a subtle shift in the meaning of the term 'change strategies'. No longer is there a commitment to change, based on passionately-held values and beliefs about what is a good life and how to assist people with disabilities to achieve their full potential and lead a valued and good life within community. The culture has shifted from passionately wanting and seeking change in the lives of people with disabilities and their communities to a culture in which bureaucratic factors such as legislation, standards enforcement and funding agreements are the driving force of change.

The evidence before me is convincing; I attend such meetings committed to assist individuals with disabilities, their families and

the wider community, in the pursuit of achieving better daily life circumstances. The challenge for me is: how do I assist people and service systems to actively seek out and
want change? It is not about enforcing change through the implementation of legislation or administration strategies.

I hear much about how we are to enforce change through the introduction of legislative reforms, the introduction and enforcement of quality standards and financial agreements between funding bodies and service providers and how best to educate people and systems about these enforcement strategies.

But there is little or no discussion about how to facilitate and foster, within the hearts and minds of people and within the core values of organisations, a desire for change, based on a commitment to achieving typical and valued lives for people with disabilities in community.
Being grumpy, I recall with fondness the commitment and the sense of seriousness and leadership that was displayed by the Federal Government during the period of the introduction of the *Commonwealth Disability Services Act (1986)*. Through focussed education and community

discussion, individuals, families and disability service organisations were shown a vision of how the policies and practices being enacted could impact on the daily life circumstances of individuals with disabilities and families and improve their situation.

I was growing confused as well as grumpy. The starting position in 1986 had changed from one of person-centredness to one of system adherence and enforcement. I am not against the introduction of legislation, standards and increasing accountability within human services, but I do not want to lose sight of that original commitment to the original vision and belief that typical and valued lives for people with disabilities could be achieved.

So how am I to survive and deal with this increasing level of grumpiness?
I call upon the past (as grumpy old men do) to look at how others have gone about maintaining a humanistic foundation when in the service of others. I am interested in what had helped to contribute to a healthy culture of focussing on people and their needs as a priority while in the presence of external influences and power.

I recall some observations I had made while a guest at a retreat at the New Norcia Monastic Community in Western Australia. This monastery is based upon the teachings of Saint Benedict, who founded the Benedictine Monastic Order over 1500 years ago. The New Norcia Community has been able to maintain their foundation values, even during times of struggle, by remaining true to sound advice from St. Benedict; sound advice which remains relevant today, both at a personal and professional level. The following considerations which St. Benedict thought essential for communities and individuals hold just as true today for an individual and organisational commitment to maintaining and enhancing a strong values base to their work.
In order to remain faithful to our cause, whether at an individual or organisational level, St. Benedict says we need to:

1. Hold and maintain a coherent values base.
2. Document and distribute the organisation’s values position.
3. Call upon supportive documented material that reinforces and supports such a values base and share this.
4. Identify and call upon others who may share the same values to become a defined and supportive community to each other.
5. Establish ceremonies and rituals that help remind us and others of what is important.
6. Take time to meditate and contemplate both personally and professionally in regards to the issues that one is confronted with and how these issues relate to one’s values and beliefs.
7. Develop and display appropriate ‘icons’ that both reflect and promote your purpose and beliefs.
8. Reflect through dedicated study in the areas that require serious and further consideration.
9. Step outside and take time to return to your roots.
10. Consider what may and will go wrong in a world that is full of complexity and fragility and be prepared for it.

If we do these things, he says we will feel strong and keep constant guard over life.

Even in time of grumpiness I can acknowledge that systems have their own beliefs, principles and practices but despite this I still have a responsibility to draw to the attention of such systems (and the people within them) to ask of themselves: Who it is who is being served by their actions and what are the consequences of such actions?

If grumpiness is one of the consequences of accepting this responsibility, then I will learn to live with my grumpiness. Bob Geldof, one of the grumpy old men interviewed in the television series gives me further permission to live with my grumpiness when he says, “If you aren’t grumpy that means that you are content with the world. And who could be that?”

So Bob has given me permission to be grumpy. And a monk, who lived fifteen hundred years ago, has offered me advice about how to manage it.

I can’t be grumpy about that.

> “IF YOU AREN’T GRUMPY THAT MEANS THAT YOU ARE CONTENT WITH THE WORLD. AND WHO COULD BE THAT?”

Keeping the focus on the person, not the service

We asked **Leanne Burke** *to describe some essential characteristics of self-governed or family-governed support arrangements. Leanne discusses how people with disabilities have achieved greater levels of authority over their own support arrangements and how co-ordinators and workers can assist by developing an understanding of their support role*

Over the past eleven years I have been employed by small services that have been established by people with disabilities or by family members of people with disabilities. In the main they were people who had some experience of traditional services and had rejected what was on offer. This experience gave them some understanding of what they did not want – a good start in knowing what they wanted. Broadly-speaking, they have all been groups of people who came together to set up small support services that would meet their diversity of needs and enable them to direct their own support arrangements. What they wanted was the opportunity to choose the most appropriate support arrangements for themselves or their family members.

In the small services that have been set up in this way, each person has individual support arrangements where and when they are needed and where possible, provided in collaboration with family, friends and community. The people who use the service are well-known, as are their needs and wants and together with family members and close allies take on governance roles as members of the management committee or directors. The service is accountable to the people who use the service and maintains a low profile in the person's life, while remaining aware of vulnerabilities. It is conscientious in building safeguards to the person's support needs and time is spent planning so that crises do not develop.

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

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

By employing his or her own workers, the person or that person's family establishes very clear authority over their own support arrangement. The role of a service co-ordinator will then be dependent on the requirements of the individual being supported. At times, the co-ordinator might act more in a trouble-shooting role and at other times assist with more deliberate proactive strategies. Responsibilities of co-ordinators include assisting with staff reviews, ensuring that workers understand their role and helping resolve any staffing issues. The person or the family has the ultimate authority over who works within their home. While the service takes responsibility to deal with any industrial issues that may arise.

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

The services in which I have been involved constantly try to ensure to make the impact of 'service' in the life of a person with disabilities as relevant as possible. Considerations such as employing the right workers, planning and implementing support arrangements and rostering workers are tailored to the needs, skills and the self-direction of the person.

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