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:

1. **Promote:** speak well of the person and ensure both staff and the person are well presented.
2. **Protect:** try to ensure secure housing tenure, excellent medical care, well trained staff, good equipment and have the capacity to dismiss unsuitable staff immediately.
3. **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: 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 more 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.