

Reclaiming Family Business

Originally published: Issue 24, July 2002.

Margaret Ward is the mother of three adult children. Despite significant disabilities, her first daughter Ismena lived in her own home for ten years, with the support of family, friends and the Homes West Association. The family's involvement in Homes West is the focus of this article. Margaret is well known for her strong, visionary leadership in the Queensland disability movement. She also played an important role in the establishment of Queensland Parents of People with a Disability and CRU.

Most families who use services have been frustrated by technocratic managerialism. They are bemused by the increasing complexity of the service system and the widening gap between the call for 'efficiency and effectiveness' and the reality of their son's and daughter's lives.

Technocratic managerialism commonly manifests itself in ongoing restructuring, increased reporting requirements, and an emphasis on management ahead of experience-based knowledge and wisdom. Families work differently. Their ways of solving human problems are messy and idiosyncratic, requiring trial and error, intuition and perseverance. Experience and wisdom allows them to think smarter as they get older and the tasks get harder.

There have been some successes in bridging the gap between the service system and families but those success have been few. Those services that have been successful have shown it is possible to work respectfully with families and shield them from the demands of technocratic managerialism or whatever fad is fashionable at the time.

The March edition [CT23] of CRUcial Times offered some strategies to service providers who want to work in similar ways. Here, I am offering some strategies for families.

Embrace the natural authority of families.

If you are unsure of your authority as a family member, I suggest you make two lists on a sheet of paper. In the first column, list all the people who have been constant in the life of your son or daughter for the last ten, twenty, or thirty years. In the other column, list all the people who have come and gone over the same period.

My guess is that your first list will be short, naming your family members. There may be others, if you are lucky, and perhaps a few faithful friends or 'extended family'. This list is valuable because these are the people who can even begin to claim some authority in your son or daughter's life. The other list will be enormous and frighteningly irrelevant.

Michael Kendrick wrote a short pithy, piece called [The Natural Authority of Families](#). I suggest you obtain a copy from CRU and stick it on your fridge. In no time you will be clear, realistic, and authoritative and you will need to be if you want to take back what is, and always should have been, Family Business.

Reclaiming Family Business.

I believe that there is 'Service Business' and 'Family Business'. Service business is the business of providing services; and Family Business governs how, when, why, and what level of service should be provided for a family member. Family Business is also the following:

- Daring to dream the seemingly impossible;
- Thinking lovingly, passionately, and intuitively about your son or daughter's life;
- Protecting the sacredness and privacy of family customs, culture and history;

- Espousing your son or daughter's beauty, gifts and talents.

And when your son or daughter cannot speak out for themselves:

- Ensuring that service providers meet his or her needs.
- Naming what is a good life for your son or daughter;
- Stating clearly what is negotiable or non-negotiable, what is acceptable or not acceptable.

If you are spending all your energy trying to get services to do the right thing, being pleasant to service workers who disregard you, or generally trying to find out what-the-hell is going on, you have lost control of what should be yours – Family Business.

Getting it back is tough. Keeping it once you have it back is also tough. However, families are doing it all the time and services, once they let go, realise that it works better when families have a say in what services do. Services also discover that when families signpost the way, there is a sense of continuity, fewer situations that turn into crisis, and less waste of time and money.

Stick to your message.

Once you are clear about your authority and your vision, you will need to stick to it. All manner of effort will be made to offer you a compromise that fits better with the service system. This can be stressful because your non-compliance may earn you the name of 'trouble maker', 'unrealistic, or even 'greedy'. The well-worn rules of action are relevant here: courtesy, truthfulness and tenacity. Because a symptom of the present service system is that staff come and go quickly, this labelling is not as damaging as it might otherwise be.

It is important to be sure that your message is, in fact, what you really want for your family member. Allies and trusted advisers can help you to double-check that what you are doing is the best way forward.

Find your allies.

There are people in service systems who do want to help families; they are usually long-term players and are skilled at minimising the effect of whatever management fad is in favour. They don't break the rules but they do know how far they can bend them. There are always loopholes and windows of opportunity when change is rife and your allies can tell you about them. They will also know other families who are thinking alike and where good things are happening. They can also warn you of the pitfalls.

Other families with the same vision as yours are important allies. It is here that ideas can be tested and modeled, using real experience and understanding. The synergy of a group of families is powerful and strengthening for each member. I believe that families do best when they join together. When you find your allies, listen to them – they may save you a lot of time and heartache.

Support people making change.

People with a disability, family members and workers have taken systemic action over the years to influence the service system to be more responsive to people with disabilities and their families. They sit on committees, write submissions, make deputations, and take legal action. It is very important that we support them.

It is almost certain that service systems and governments will become even more complex and technocratic over time, and that there will be ongoing changes and fads in management.

We cannot depend on some management technology, financial theory or restructure to bring sense to the service system. It will be the culmination of systemic and individual actions by concerned citizens, along with families and people with a disability that will continue to call the service system to order.