

## Listening with Intent and Acting with Purpose

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Our work on person- and family-centredness draws on two powerful aphorisms. The first is Henri Nouwen's exhortation 'to live the questions'. The second is Ruth Gorman's call to 'listen with intent and act with purpose'. We are privileged to be involved with a family who has long been part of the Mamre Community. This family is currently engaged in planning for the future with Rod: their son, brother, nephew, and friend. Our involvement with Rod and his family deepens our understanding of what 'listening with intent and acting with purpose' means in practice. Below we explore the questions we are 'living' as we endeavour to work with Rod and his family in person- and family-centred ways.

### **Can we reasonably dream of a world where people, whatever their race, religion, culture, abilities and disabilities, can find a place and reveal their gifts?**

Person-centred and family-centred approaches are helpful for planning and building supportive networks and lifestyles. They support people to find their place in the world, to reveal their gifts to us and to contribute. Unfortunately there is a strong tendency for good concepts such as these to become over-formalised and bureaucratised. The consequence is that people with disabilities continue to be regarded as 'special' and their lives become highly planned, coordinated and reviewed to achieve goals. Yet planning will never result in a happy, tidy, well-constructed future. The process will always be an evolving one as we form ongoing relationships – relationships being far more important than rules – engage in good planning, find good people, participate in ongoing conversations, share insights and explorations, make constant adjustments and recognise that this is how it is in all our lives.

For example, in Rod's life, family, friends and support people have all been challenged by Rod in many ways. Sometimes, we do not understand what his behaviours are indicating. However we also believe that he is a 'great bloke'. He is known and respected by all of us. Coming together to assist Rod to find ways to move into the next stage of his adult life so that it is truly *his* life has been a heart-warming experience. The struggle to get to know him, to understand him, and to communicate with him is balanced by a strong belief in possibilities for him through recognising his capabilities. There is agreement in his network that having listened with intent, it is now timely to step out and 'act with purpose'. The people in Rod's support circle have agreed to support one another in this resolve.

### **Whose life is it?**

The second question we live, 'Whose life is it?' sits at the heart of person-centredness. This question contrasts person- and family-centredness with service-centredness. History shows that people's lives have often been orchestrated by what services were able to do for them, by the availability of funded resources, and by a predominantly custodial model. Life was equated with a place in a facility, efficiency with the filling of beds, and service with support formulae. People were not in control of their own lives but had to fit in to a designated service. This strategy emanated out of a focus on the disability rather than the person.

Movement away from this service-centred approach is only possible when the focus shifts from the group to an individual and to the individual's hopes and dreams. This change also assumes the building of formal and informal networks around the person, and the organising of supports to assist the person where assistance is needed. This is an extremely personal – not merely individual – approach. It is dependent on the formation of trusting, intentional and resilient relationships with people who will ensure that the person stays at the centre and that planning progresses into some positive outcomes in real life.

One of the positive outcomes of our planning sessions with Rod is that he is now incrementally moving away from his parent's home to his own place. His network of support, both paid and unpaid, continues to back him. Life is messy at times and arrangements often need to change. This necessitates flexibility by everyone involved. No doubt there is some discomfort for Rod as he moves out of his

comfort zone, and certainly it is difficult for his parents to let go and to live with a degree of risk. However, there is a belief that Rod wants to move forward in his life and it is up to those with him to find ways for this new direction to happen, by continuing to listen with intent and act with purpose.

### **What is 'family business' and what is 'service business'?**

As service providers it is easy to fool ourselves into thinking that we are working in truly person-centred or family-centred ways. We can find ourselves engaged in practices that belie our stated belief in the need for individuals to own their own lives. For example, sometimes as workers, we facilitate planning sessions with a person and his/her network and then immediately pick up the planning notes from the meeting and assume ownership of them. It's imperative that we ask, 'Whose plan is this?' 'Who owns the notes?' 'Who owns the communication book?' We need to find more respectful ways of determining with the person how the transfer of information is achieved, how privacy is guarded and how the person can stay more in control of his/her own information.

Partnership is a term that we use more and more without a lot of attention to its meaning in a particular context. If the partnership is between a person or family and a service then it is important for there to be an acknowledgement of what is 'family business', what is 'service business' and of the interface between the two. In this context, partnership is about how family members and professionals work together to achieve the outcome that the person seeks. It requires identifying the things that are in partnership and the things that are outside either partner's control, such as some aspects of funding. The concept of partnership assumes transparency, clear communication, information and each partner respecting the role and boundaries of the other.

For Rod, change requires the involvement of many people with different roles and responsibilities, different relationships and unique histories with him. Partnership in this situation is viewed very positively and has been characterised by a deep respect for the different way in which each person contributes to the overall change for Rod. The lynch-pin is effective and clear communication with all those involved.

There is also a need for clarity about decision making processes, to be clear about what decisions rest with the individual or family and which decisions are in the domain of the service provider. Clearly some matters need to be acknowledged as family business only and others remain the responsibility of the service. This means that agreements made are not altered without input from the other parties involved. Rod's plan has been developed with his families, friends, workers, and allies. However Rod owns the plan. He and his family have final say about what is in the plan and how this is implemented. No changes will be made without his consent and that of his family. As his service provider, Mamre recognises its accountability to Rod and his family and also to the funding body.

**What do you really believe?**

The fourth question we are living is rooted in values and requires some honest reflection if we are to engage in this process with an individual. It suggests that in thinking about how people with disabilities can find their place in the world and reveal their gifts, the starting point is actually a strong belief that this is truly possible. Further, that it is much more ordinary and simple than we imagine, or at least as much as anyone's life is simple and ordinary. Over the years, it has sometimes been a struggle for those who know Rod to believe that he would live in his own home, have a network around him, have a healthy and involved lifestyle, be out and about doing things he loves, making his own mistakes and living with the consequences.

Living the question of what we really believe requires us to challenge ourselves about the degree to which we are open to possibilities for the person who has a disability. It is about being totally committed to the idea that people with disabilities can lead ordinary lives, and being strong in this belief so as to empower others to think differently, and to be able to ask the alternative question, 'Why not?'