

Listening Differently

Patricia Fratangelo

Patricia Fratangelo is the Executive Director of Onondaga Community Living (O.C.L.) a relatively small organisation in Onondaga County in central New York. Pat has worked with people with disabilities for over twenty years; the last thirteen at O.C.L. Last year Pat visited Brisbane to share her experiences of working in person-centred ways. In this article Pat builds on this work, by exploring how we can learn to listen more deeply to people.

When we are talking about developing services for those with high support needs, we often fail to think about normal lives. Typical homes with people who are loved and cherished are often not the first options discussed when people are perceived to have a disability. Service systems and professionals have developed a different way of supporting and maintaining those who do not fit the typical mould. Traditionally, people who are perceived as unlike the typical populations are pulled from the roots of family, neighbours and friends and are served in a system of supports that is very foreign to them. Strong parents and advocates, who are not afraid to fight, have worked long and hard to break out of the traditional mould that meets few people's true needs.

A normal life, along with the attributes that each person brings, should be paramount in all decisions that are made. But unfortunately normal lifestyles and personal gifts are often clouded or unrecognised because they are disguised by people's perceptions of a disability and their assumptions about appropriate models of support. Many of the individuals I have known are challenging to most, difficult to many and extremely misunderstood. They have been institutionalised, incarcerated, managed, medicated, controlled, clientised and victimised. A normal life is seen to be far-fetched, or even unobtainable, by those who see the disability. The person is then not recognised for the gift of who they are, but instead they are seen as the perceived difficulty that they bring. This is illustrated by the experiences of Susan, a young woman I have known for many years.

Susan was institutionalised for most of her life. In her mid-twenties, she was finally accepted into a group home. At this residence, she became highly agitated every time someone left the house without her. She repeatedly damaged property and injured others. Susan was purposely communicating what she needed, but not in a way that was easily understood by others. Susan knew what she wanted but staff did not understand her.

Susan has many gifts, one of which is the gift of personal determination. No matter how much she was controlled, punished, or medicated, she kept trying to communicate to the staff what she felt and needed. Realising that Susan was trying to tell us something was the first step in changing her life. Susan did not change, it was the staff that learned to change their ways and to begin to understand what Susan was trying to tell them. It was finally recognised that Susan just wanted to be on the go and did not want to compete with others from the group home.

After much planning, Susan moved to her own home with the support of typical community people. Because of her own determination Susan now lives a more peaceful life. She does not have to live with or compete with others. Susan now lives peacefully

with Ingrid, a person who loves and respects her. She lives in a beautiful home with stylish furnishings and a person who enjoys her company. She no longer damages property or injures others. She has deeper relationships and more involvement with her family than she has ever had before. These relationships were paramount to her but highly disregarded in the past.

Developing a more realistic and normal life based upon the attributes that Susan has is not far-fetched when one lets go of the perceived disability and sees the strengths and gifts that Susan brings to her life and the life of others. Susan gives to us the gift of deepening our ability to listen. She helps us to be more thoughtful as we consider what services she really needs. She helps us to think about the safeguards that are really necessary in her life. She has taught those around her how to listen differently to perceived problems, to be creative and flexible, to believe her and to work towards her personal dreams. Her voice has finally been heard.

An earlier version of this article appeared in the Mamre Newsletter, March 2004.