

## What is Involved in Delivering a Quality Service for People with Disability - An Advocacy Perspective

*Josey McMahon works with great passion and commitment in her dual role as manager and advocate at a small community-based independent advocacy agency that provides individual social advocacy on behalf of vulnerable people with disability. In this article, Josey discusses the role of advocacy in safeguarding the lives of vulnerable people with disability and the importance of providing both relevant and potent service provision to those who are disadvantaged and viewed differently by society.*

Many service providers and governments place great faith in the belief that a Quality Assurance (QA) system will assure that human service organisations will provide those they serve with a 'quality' service. Similarly, many people with disability and families place great faith in the belief that resources and funding will provide them with a 'quality' service. As an advocate I sometimes hear that families believe that a funding package will make all the difference to their family member and themselves and that life will be improved. Yet, receiving a funding package does not guarantee that a person's needs will be met.

Providing a service of excellent quality does not necessarily involve having a funding package. There are many factors which determine if a service supports people well. One of these factors is having people involved with the service, both in positions of leadership and in providing support to people who use the service, who are passionate about what they do, who have a genuine desire to do good on behalf of people rather than do harm and are people with values that are, at the very least, based on social justice principles. Another factor is having people involved who are external to the service and who are encouraged and welcomed by service providers to participate in assuring that the service meets the needs of the people served. This can occur in many ways. One important way this can occur is when people act as independent advocates on behalf of people who use the service. Advocacy can be an important safeguard for ensuring that service provision is relevant to each person's individual needs.

As an advocate I hear many stories about how services may not provide support to a person which meets their needs. Recently, I heard a story from a parent whose family member was receiving support from a service that was 'quality assured'. The parent advised that they had gone to the home of their family member to find that their adult child, who was totally dependent on the service for all aspects of their personal care, had not received the appropriate care. In fact, the parent reported, that had they not gone to the home at the time when they did, they felt their family member most probably would have died. The service provider had ticked all the boxes on the paperwork, indicating that the necessary procedures had been carried out appropriately; however, the reality of what had occurred was quite the opposite. The parent was fearful about confronting the service and raising a complaint, as the service provider might either withdraw support, or reprimand them or their family member in some way. The parent was well aware that the service concerned had previously tried 'exiting' their family member on the basis that the person's needs were too complex and they should be placed in a nursing home.

Strong independent advocacy was needed in this situation. Independent advocacy is based upon taking positive, ethical action on behalf of the sincerely-perceived needs of the vulnerable person with disability and being on their side and their side only. It is about being autonomous and independent of the service system and acting with minimal conflict of interest and continually focusing on the fundamental needs, welfare, interests, and human rights of the person with disability. It is done with vigour and with a sense of urgency and remains loyal and accountable to the person over the long term. At times, advocacy can be

costly to the person advocating or to the advocacy agency. This is because it challenges the dominant paradigm – the often poor practice in which people with disability are viewed negatively and therefore treated with contempt and as second class citizens.

When people have no family relationships, few or no friends and are totally reliant on support from a service, independent advocacy is particularly important. In these kinds of situations, people are very vulnerable and harmful things are more likely to happen to them. Vulnerable people with no voice, choice or influence over how they live their lives need independent advocacy as a protective safeguard.

When a vulnerable person with disability has an advocate in his or her life, the person is more likely to be treated with dignity and respect. A prime example of this is when a person with disability is a patient in hospital and is reliant on the staff for all aspects of their personal care needs, particularly when the person is unable to communicate their needs, the hospital staff is more likely to treat the person with little dignity and respect. However, I have noticed that if an advocate visits, bringing flowers or personal items for the person, then hospital staff will improve the way they treat the person.

Human service organisations supporting people with disability need to establish a culture which holds a positive image for the people they support and has a personalised vision of a good and valued life for each person being supported. Often it may only be an advocate who has that positive image and holds the vision on behalf of the vulnerable person with disability. This is often because many families have been ostracised and are not encouraged to stay involved and ultimately have been pushed out of the person's life. Their vision for their family member has been eroded from very early on.

If there is no positive vision for the person then it will be very difficult for the person with disability to plan and achieve a positive future. To begin to build a vision of a good life for the person, it is vital to get to know the person well and to engage in real conversation with them, and with any family and friends still in their lives. For an advocate to provide potent advocacy they need to build a strong relationship with the person and know the person well. This is an important element in the advocacy practice.

A service provider striving to achieve high quality service provision would ensure that they have a right relationship (a relationship that is respectful and professional) with the person being supported, their family and friends. It would seek to ensure that the person being supported is seen and treated with appropriate respect, integrity and valued and is enabled and encouraged to be decisively influential in how they are to be assisted. If the person's support needs are such that they are unable to be involved in designing their support, then their significant others should be encouraged to do so. This is a legitimate advocacy role for the family and, if the person has no family, a legitimate role for an advocate. Natural unpaid relationships with family and friends provide a sense of belonging, acceptance and security and can never be replaced by paid support services.