

Communication – getting it right

*In his third article in this series on communication, **Tony Bamforth** looks at the quality of communication with people in their own home. For people with learning and communication difficulties, he says, this is where it is most important.*

Research for this article involved conducting interviews with both family carers (Jean Willson and Clare Palmer) and support workers (Alison and Shola), and led to some profound yet simple insights into what is involved in 'getting it right'.

The quality of communication with people in their own home is the focus here. For most people with learning and communication difficulties, this is where it is most important. The key finding here is undoubtedly the crucial importance of continuity, both in people and approach. Here, I give examples of what is possible when real effort is put into getting it right and what we risk if we fail to afford people their most basic of human rights – the right to be heard and to make real choices.

Victoria Willson is a woman in her 30s with no formal methods of communication. She has serious health conditions which require ongoing intensive involvement from a wide range of health care specialists, including regular hospital treatment. Despite all this, Victoria continually exceeds all medical expectations in terms of her lifespan and her ability to respond positively to an exhausting range of medical interventions. Victoria strikes me as a woman who knows what she wants from life and is determined to live it. Most importantly, she has people around her just as determined to support her to do so.

When I visited Victoria to interview her keyworkers, I was struck by the atmosphere in the home, 'home' being the operative word. Victoria's home felt like a home. The sad truth is that for most people with such high support needs, it is still very much the exception for their home to feel like a home. It's the small things that make the difference; for example, when I called to make an appointment, the support worker answered the phone with, "Victoria's home, can I help you?"

I wanted to find out what the difference was between Victoria's home and other places where people with very high needs live. The deputy manager, Alison, had previously worked in a neighbouring borough with other people with learning and communication difficulties. Despite the tenants there being more able than Victoria, their ways of communicating were very basic. Alison said their communication seemed significantly under-developed in relation to their potential abilities.

What was the difference for these people? First, there was very little family involvement in the lives of the individuals; consequently, the tenants were much less sociable. This role of involvement in an individual's life doesn't necessarily have to be taken by a family member, Alison added, although in Victoria's case, it is. A long term friend or advocate could take on this role equally well but, Alison was at pains to stress, continuity over a significant period was of crucial importance.

Victoria's family are able to provide key information about her history, likes and dislikes. This ongoing regular contact with family provides an added layer of monitoring and a more profound and informed interpretation of behaviour, in particular of any changes in behavior that might happen. Is this any different to what family or long term friends provide for any of us? The difference manifests itself in the expectations people with learning and communication difficulties have of others – an expectation that behaviour WILL be interpreted correctly and that appropriate action will follow, that they can and will be understood. This is the key concept to grasp. A virtuous circle of engaging meaningfully with others is set in motion.

Both Shola and Alison had a clear sense of value and appreciation of this ongoing contact and involvement from family members. Alison was quick to admit that one of the skills learnt in her current role was how to relate effectively with family members. Support workers take over part of the role previously undertaken by the family. In keeping this connection alive through regular updates and reflection on any significant changes in behaviour, support workers are providing a very real form of continuity. This in itself enables even relatively new support workers to quickly develop a deep understanding of an individual and more importantly to allow any prejudices they might have assumed to be challenged. Given the obvious rapport and sense of ease between Alison and Victoria, it was astonishing to consider that Alison had been working with Victoria for only six months.

Victoria is very easy to engage in communication, keen on eye contact – as I can testify. She was obviously interested in finding out what I was doing visiting her and did not shy away from making regular eye contact with me. In contrast, Alison told me about a man she worked with in her previous role who had lived most of his life in a long stay hospital. He was so unused to people paying him regular attention that he found eye contact uncomfortable.

This made it difficult to communicate with him, and the experience of providing support frustrating and largely unrewarding.

It was clear that Victoria's support workers have developed very strong trusting relationships with Victoria. It wasn't even necessary to ask for examples of ways that communication takes place as it was evident throughout my visit. Soon after I arrived, Victoria gave one short scream and started biting her hands which Alison quickly, and correctly, interpreted to mean "I'm thirsty,

"I want a drink!". As soon as she handed Victoria a drink the behavior stopped. Shola then asked Victoria if she wanted breakfast. To indicate she did, Victoria lifted her head and simply looked towards Shola. When breakfast was ready, Shola asked Victoria to help her. She held a spoon out towards Victoria who reached out with her hand and fed herself quite happily. When breakfast was finished, Shola got Victoria's coffee cup from the kitchen.

Victoria made another sound to indicate she wanted coffee. Victoria is keen on using objects of reference; for example, a coffee cup to indicate coffee, an apron to indicate that food is ready. Although many of the objects had been developed in the past, staff at Victoria's home regularly come up with ideas for new ones in team meetings. This in itself is a creative process the staff relish. It isn't so critical what the object is as long as it makes sense to the individual and is used consistently so they can build up recognition of the object's meaning.

Both Shola and Alison were emphatic that learning how to communicate makes the work of supporting people so much easier and enjoyable. And, of course, it is one of their basic human rights. I asked Alison what she would say to a support worker in a different place who said the person they supported wasn't able to communicate. Alison laughed, thought for a moment and said, tactfully: "I'd say they are mistaken. I don't think there is one person alive who doesn't communicate – they just need to get to know the person, their likes and dislikes. I would also say that their horizons are limited and they were doing the person they support and themselves a disservice by making that assumption".

In the first article in this series, Wendy Tuson (Speech and Language Therapist) described a technique called 'intensive interaction', employed to develop individualised communication. Victoria's support workers employ this technique on a daily basis as a part of their routine. Staff keep a note of what they have done to interact with Victoria, describe the session, any significant occurrences and then evaluate how successful the session was. In practice, this looks like natural playful activity. As such it can be employed at any time and in any place.

Alison began by involving Victoria in moving in time to music that was playing. Shola then demonstrated 'intensive interaction', spinning strings of coloured beads with her fingers. Victoria had been playing with some beads earlier that morning so Shola encouraged her to do this again, this time with Shola and in time to some music Victoria was obviously enjoying. Shola then invited me to introduce myself to Victoria by allowing Victoria to stroke my hand then stroking her hand in return. Shola explained that Victoria is very tactile. She has developed a whole system of touch-based communication with her support workers to help them work together; for example, a touch on Victoria's shoulder indicates staff want her to lean forward, a tap on the legs, to stand up. These systems of communication appear very simple and straightforward, in practice they take a lifetime to develop and require constant and patient reinforcing to ensure they are not lost.

For Jean and Clare, who also has a daughter with learning and communication difficulties, the most common frustration is dealing with people in authority, who consistently fail to appreciate how much time and effort is required to get it right. Not only that, these very same people also fail to appreciate how much effect this has on the quality of life of all concerned, not just people with communication and learning difficulties themselves but also support workers, families and friends.

Most damagingly, they also fail to appreciate how frustrating it must be for people unable to communicate using speech or signs, who have no-one around them with the skills or insight to even try. There is a tendency amongst service providers and professionals to treat family members of the people who need support with suspicion, to disregard their knowledge and understanding of

the person and to start from scratch. In this, professionals sometimes appear arrogant and seem to assume that because they are 'qualified' they know best what works for people who need support. This assumption often conceals a lack of critical reflective practice. We need to be able to challenge the way we do things if we are ever to improve and do our best by the people we support. This must involve making the best of all the information we can gather about people. Family members most often know the most and it is therefore crucial to develop good relationships with them. Any information we can get from family members should be treated as gold dust.

Thankfully, there are signs that in some areas the real value of input from family and friends is recognised; for example, in the methods of inclusive consultation described in the second article in this series. This research into communication for people with learning and communication difficulties has led to a profound realisation that the wealth and complexity of issues involved are often chronically underestimated, even by skilled practitioners. This is surely why services for people with these difficulties are for the most part woefully inadequate, if not actually abusive. It would also explain why loving and caring family members are driven to distraction and at times blind rage by the barriers they face on a daily basis, simply trying to make sure their loved ones are treated as human beings. A persistent, consistent and dedicated approach is required at all levels to effect the change that is so desperately needed, if we are to see any major change in quality of life for people with learning and communication difficulties.

Tony Bamforth is Assistant Director of the Elfrida Society.

Community Living Volume 21, No2 – 2007