Conversations without words

Successful interaction with someone with complex and multiple learning disabilities can be difficult, but there are strategies to achieve this, says Dr Mark Barber.

I recently watched a teacher working with Tom, who was 13 years old and had very complex intellectual disabilities. Tom was sat in an armchair, repeatedly turning his head from side to side. He commonly blew raspberries and occasionally made open vowel sounds that coincided with him forcibly exhaling after holding his breath for several seconds. When he held his breath he would often close his eyes and smile.

Tom occasionally pushed his shirt collar into his mouth with his first finger, where he would chew rhythmically on the fabric for short periods before spitting it out to resume his cycles of blowing and breath holding. His arms and hands were relaxed and generally stayed in his lap. When he became still and contemplative between pulses of activity, Tom held his hand in a relaxed fist, with his first finger gently extended. He could sit upright without assistance, but had no independent mobility.

As far as it was known, Tom could see and hear; he would touch faces that came within reach and would frequently pick up and shake noise making toys when they were placed next to his hand. Although he rarely responded to voice sounds, he occasionally responded to sudden noises that occurred close by. Tom has never been noted to gaze at or show interest in events, people or objects when they are more than a metre away.

The teacher, Shirley, sat directly in front of Tom, with her face less than a metre away from his. She talked to him in an animated voice, asking playful questions and lightly touching him with her finger. She used the rhythm of her words to set the pattern of the pace of her touch, which moved in arcs from Tom's chest to his face. If she felt his concentration on chewing distracted from his focus on their shared time, she would gently take the collar out of his mouth. Before she did this, she tapped his cheek "to distract his focus from the sensation of his collar in his mouth" as she removed it.

Shirley periodically paused in her movements and vocalisations and waited for Tom's gaze to settle on her, or lean toward him when he paused, to encourage him to touch her face. Occasionally she would encourage this by taking his hand to her nose, saying "Look Tom, you're touching my nose." Then she would touch his, repeating "Nose, Tom's nose," as she did so. Shirley had noticed that when her face was close to him, but turned away, Tom would reach out and touch her face and turn it so that it faced him directly.

Shirley believed that his attempts to reorient faces reflected his interest in other people and that his actions indicated that he was an intentional communicator. In addition, Tom could reach for his favourite dessert and consume it using a spoon and slope-sided bowl, and hit a switch to activate a vibration toy or a BigMac [communication device] with a 'hello' message on it.

Based on these observations, individual teaching plans focused on encouraging him to explore a greater range of sound-making toys and switch outcomes, in addition to helping him to use a 'yes'

and 'no' switch. Shirley had heard about Intensive Interaction and had spent many teaching sessions imitating his head movements and vocal sounds, as well as playing peek-a-boo and anticipation games of "1-2-3 tickle". She was concerned that Tom only seemed interested in what she called 'self-stimming' and did not seem interested in people other than when he reoriented her face when it turned from his.

With the best of intensions we routinely impose our idea of what is pleasurable, appropriate and interesting onto people like Tom, often with the assumption that they will come to develop understanding by repetition and immersion. However, many of the ideas and activities we provide can actually become sequences of unrelated 'incoming' events for the person experiencing them without an understanding of 'why' they are happening or what they relate to.

Are objects more interesting than people?

Unless activated or touched, objects are entirely predictable and don't intrude or distract ones attention from a current interest. People, however, are very complex, move without warning, frequently make mysterious noises and sometimes even pick you up and put you somewhere else.

Tom's apparent interest in objects rather than people around him might suggest that he finds them much easier to understand. Objects tend to have a smaller range of 'things that they might do' than people; it is easier to get a reliable and consistent response from them and they don't have their own agenda, neither do they walk away unexpectedly or get distracted.

While we can only speculate about what it is like to be Tom, we can safely assume that most of his days are filled with sequences of events that while possibly being familiar to him, simply *happen*, engulfing him in unwanted sensation, without apparent cause or reason.

Being unable to move around and explore independently, or make much sense of what is happening, Tom's experience of consciousness has been sculpted by helplessness rather than social exploration and agency. This frequently results in an orientation towards objects rather than people.

Helplessness

It is uncontroversial to state that for many people with complex intellectual and multiple disabilities, like Tom, achievable and readily available distraction from helplessness and boredom is often provided by focusing on generating interesting or pleasurable sensory events e.g. Nind, M & Kellett, M. (2002); Samuels 2003).

It can be speculated that, given his habitual focus on self-directed sensory activities, many of the suggested activities for Tom to experience are received as sensory intrusions. For Tom, these may well be kept at bay by the internal 'events' that he has learned to provide for himself.

His choices of activities not only provide repeatable interest, but may also provide him with some sense of self determination that is lacking in other aspects of his life: alternating deep breathing with breath-holding can create euphoric states and visual disturbances, while repetitive movements can provide emotional comfort. While his persistent chewing might be related to these cycles of activity, it might also indicate the need for a speech pathologist, occupational therapist or indeed dentist and this should be investigated.

Is Tom an intentional communicator?

Shirley's belief that Tom's actions on faces and objects suggest that he is an intentional communicator was almost certainly misplaced. Intentional communicators use;

- Non-verbal or gestural behaviours coordinating people, or people *and* objects
- Persistence until their (inferred) goal is achieved
- Satisfaction on achievement of their inferred goal
- Attempts to repair (i.e. through repetition or modification of communicative strategies) if the correct goal is not achieved

See e.g. Bates, E., Camaioni, L., & Volterra,V. (1975); Bates, E., Benigni, L., Bretherton, I., Camaioni, L. and Volterra V. (1979); Harding (1992); Stephenson & Lindfoot (1996).

Tom had never been seen to demonstrate any attempt to indicate or move his gaze between an object or event and another person.

Simply reaching out for an object or indeed activating a switch is not intentional communication: communication is something that happens between people. The intention to cause an event or the action of picking something up is not a communicative act per se.

Inferences from Tom's actions on objects

Tom's ability to turn faces towards him might be linked to his actions on other objects that are placed within his reach and does not necessarily constitute a social act. Tom's interactions with objects placed near his hand suggest that he may be interested in them when they appear, due to their novelty, or because he recognises that he can generate a reliable, satisfying or enjoyable event with them.

But his complete lack of interest in the same objects when they are just out of his immediate reach might be taken to indicate something else. Despite his age, and undoubtedly due to his lack of mobility and experience, Tom's understanding of objects that are beyond his reach may well be limited to a few fundamental strategies. Of course, it is also possible that he has difficulty judging distances, or keeping his balance as he reaches out, although he seemed quite relaxed in his sitting position.

For someone with complex intellectual and multiple disabilities who cannot move around independently, their encounters with objects are likely to be largely defined by long or short distance reaches and what falls within them. What is out of reach does not really matter to Tom. In typical development, it is only when independent mobility emerges that learners begin to code their environment in terms of where objects are in relation to each other, rather than where they are in relation to the learner themself. (For more about this see e.g. Bremner; 1994)

When the critical experiences that shape how someone understands and interconnects their experience of the world are disrupted by intellectual and physical disabilities, drawing inferences about learning becomes very unpredictable . The fine detail of the disruption that Tom's lack of independent mobility causes for him will always be uncertain, although it will clearly interfere with the manner in which his learning about 'causality' (Bremer 1994) emerges and interacts with other areas of experience and learning.

Looking for Tom in interactions

While Shirley ensured that Tom was involved in open-ended social activities, is it possible to find a more interactive way of trying to engage him? Can we use the things that he seems to find interesting as a context for interaction? Is there room for being with him in a manner that relates more to how he finds interest and enjoyment in his life?

Although she was talking to him and augmenting the sound and rhythm of her voice with touch, Shirley was in charge of the content of any interaction between herself and Tom. How much more interested would Tom have been if her sounds and touches responded to, or had been linked to the sounds he was making?

Was Tom watching Shirley or was she simply in the way of his gaze as he concentrated on the internal sensations that he was generating for himself? She may have confirmed whether she was actually on his 'intellectual radar' if she had moved slightly to one side. Would his gaze have followed her? If it did then at least she would know. In the absence of this knowledge she continued to touch him and address him using sounds that, to Tom, might be as insignificant as the other sounds that continually assail him as he free-falls through Shirley's choice of activity.

What might have happened if she had waited until he paused in his activity and then made some of the sounds that he routinely produces and apparently enjoys?

Knowing that Tom usually pauses or rests for 5-10 seconds of every minute or so of activity, Shirley might have used these times to try to intrigue him by doing something he might recognise as being connected to him e.g.;

Making his vocal sounds while he was still, but giving way to him when he restarted his activity or vocalised again, and then repeating this process in a burst-pause sequence

Extending her finger like his and placing it end-to-end with his, gently bumping into his in the rhythm of the chewing/sucking pulses he used and then pausing to see if he attended or moved his hand closer to hers

Consider waiting for him to pause his chewing pattern and respond to it by gently squeezing his shoulder, reflecting or 'echoing' his rhythm and then watching to see if he showed any recognition or interest before he restarted his rhythmic pulses of movement.

These types of response use the rhythms and sensations that Tom clearly enjoys and fixates on and imbues them with the potential for a sequence of response. Persisting with them, unless he had shown displeasure or avoidance, may have attracted his attention, because in addition to being wholly familiar, and *'of'* Tom, they may have been interesting because they were slightly different from the usual manner in which he experiences them.

Shirley might also have considered responding to the raspberries he blew, as they are loud and clear and difficult not to hear – as well as being pleasurable for him. As she had positioned herself so close to him, she might also have considered placing her hand next to his, so that if he reaches for it, she

could acknowledge this with big dramatic smiles, joyful vocal inflection and even a celebratory blow of a huge raspberry!

Tom's perception of language

To those who use and understand it, language is made up of interesting and meaningful sequences of sounds. But there was little in Tom's behaviour that suggested that he shared that interest or drew meaning from it. Tom is surrounded by vocal sounds – from his parents and siblings, the people who educate and support him, his class peers, and the other students on school bus. But it appears to have no more significance for him than the sound of the air-conditioning, the birds in the recess area or the traffic. Language appears to be just a part of the ambient noise in his life.

Communication or performance?

In isolation, Tom's action on a BigMac is similar to that of someone else using an augmentative communication devise to say 'hello', but there are also crucial differences. When Tom uses it, the colourful devise is presented to him and then withdrawn when he has activated it.

As Shirley could relate no other examples of Tom's interest in greeting another person, or settling his gaze on a nearby face, it is fairly safe to speculate that he touches the devise because it has arrived within his reach, and/or is brightly coloured and/or is associated with making a sudden/interesting sound when touched. On investigation, when the devise was left within his reach he touched it irrespective of whether there was a message on it.

Using an augmentative communication devise to say 'yes' or 'no' requires that the user understands the communicative nature of their action (i.e. is an intentional communicator) as well as being able to 'read' the situation which announces the choice. I do not wish to labour a point, but although we should never dismiss the possibility that someone may be attempting to communicate, we should also concertedly look for supporting evidence from other potentially social exchanges or opportunities before forming an opinion. Indeed we should create frequent social opportunities to both confirm the degree of likelihood of whether the person is attempting to communicate and also to inform ourselves of the type of encounter the person is most interested in. This process should not involve the systematic trial-based training of the *performance* of communication. Communication is not a performance to be trained in order to create a facsimile of a social exchange, without any understanding of what underpins interaction

Towards being social and involved in the process of communication

Even with the best of intentions it is easy to default to placing learners with complex and profound intellectual disabilities in contexts and settings which appear to be socially appropriate rather than which involve or interest them. Access to varied and socially valued experiences is an important aspect of promoting social inclusion and developing positive attitudes. However it is equally crucial that learners experience a range of varied social encounters which intrigue their attention and provide ample opportunity for regular exploration of the social impact of their actions and involvement. To benefit from these encounters, they must be frequent enough to be familiar and interesting enough to be memorable

Where to next?

Earlier in this article, suggestions were made of ways that Shirley might have acted to intrigue Tom's attention. Once intrigue is accomplished – what next? How do we go to the next level? When will the person begin to communicate with intention?

When we look for 'progress', we frequently have an idea of what it is going to look like and fall into the trap of becoming choosy about what we accept, or of attempting to speed it up. We can be sure that Tom is doing everything he can to make sense of his experiences. The idea of practicing skills does not exist in Tom's world. His encounters with the world do not suggest that he is able to 'time travel' in the way that symbolic learners can. Symbolic and abstract thinking allows us to project possible futures and consider the pros and cons of alternative strategies. Tom appears to be in 'now' rather than 'soon'.

Predicting the visible outcomes that will announce Tom's learning, or the particulars of how his behaviour will change because of it, is largely futile. It is much more valuable to be sensitive to and monitor the emerging changes and degrees of diversity (Hewett 2011) in the way he explores the events which he causes, or attempts to extend encounters. Communication learning is not a linear process because it is action learning – his attempts to find patterns of response are shaped by his perspective of his experiences, not ours.

There is no 'next level' in Intensive Interaction. The search for 'the next level' is usually prompted by what can, for the practitioner often feel like repetitious routes and constant themes of interaction. These themes or 'formats' are important, because the learner relies on predictable structures as reference points from which to be able to explore subtle variations and the boundaries which mark the edges of similarity.

In this article I have suggested harnessing what has previously been socially isolated activity and using this as a context for the beginning of social interaction. The practitioner may have to investigate several approaches to responding before finding an aspect or facet of the person's focus which they will recognise as consistently coming from 'somewhere other than them self'.

The investigation feels like the opening gambits in a conversation at a party between two strangers, which meanders around topics until enough common ground is found to enable a mutually satisfying conversation to proceed. Intensive Interaction involves a similar process, although the onus is on the practitioner to use their skills as an experienced communicator to recognise a topic in their partner's behaviour which they might be interested in sharing.

When both participants are aware of the contribution of the other, successful interaction can take place

When both participants are aware of and recognise the contribution of the other, successful and sustained interaction can take place.

It is not the ability of the learner which is important in Intensive Interaction, but the ability of the practitioner to adapt their skills as communicators. Practitioners reply to the learner's activity in a manner that suggests and encourages the sequential nature of a social exchange. In Intensive Interaction, conventions of communication are relaxed so that 'that which the learner can already do' is all that they need to do to take part in a sustained and intellectually 'nourishing' exchange.

When attempting to strike up a conversation with a learner it is important to follow rather than lead. But it is equally important to monitor whether the learner is returning to activities or varying their cycles; e.g.

Tom blows a raspberry> Shirley imitates it> Tom holds his breath> Shirley waits> Tom vocalises> Shirley vocalises in kind> Tom moves his hand to his mouth> Shirley intercepts it and does a gentle 'hi5'> Tom holds his breath> Shirley waits> Tom vocalises> Shirley imitates it> Tom blows a raspberry> Shirley imitates it> Tom blows a raspberry> Tom moves his hand to his mouth> Shirley misses it and so waits> Tom blows a raspberry> Shirley blows a raspberry> Tom blows a raspberry> Shirley blows a raspberry> Tom holds his breath> Shirley waits> Tom vocalises> Shirley imitates it> Tom holds his breath> Shirley waits> Tom blows a raspberry> Shirley blows a raspberry> Tom blows a raspberry> …

In this example, it is good that Shirley is not responding differentially – i.e. she is not deciding which of his actions she is prepared to respond to; she gently follows his lead and replyies It is to be hoped that she is beginning to notice that he blows quite a lot of raspberries directly after she has, but not vocalise after she does. Maybe when Tom next pauses, she might try blowing a raspberry herself to see whether this provokes a like response. If it does not, she might keep her eye on how frequently he blows raspberries after she has, and wait to see what emerges around this motif.

The task of the more skilled participant in the exchange is to provide a responsive and flexible sounding board which adjusts and accommodates the learner's contributions in a manner which encourages further turns to be taken

Over time and repeated encounters, these patterns of mutual adjustment eventually establish themselves as shared conventions or 'formats' (e.g. Bruner 1981). It is important to allow any notion of 'the content' of an interaction to be obscure and to assume no intrinsic meaning, because it is structure of the exchange which is important. Curiosity and enjoyment fuel repetition. The practitioner should be aware of and respond to loops and motifs by acknowledging them and returning to them in subsequent interactions.

If the conversation proves to be particularly enjoyable, either partner might remind the other of it in subsequent encounters and like any conversation, the enjoyment will increase as the relationship becomes established. The potential diversity will increase as the shared ground grows and wealth of reference points progressively builds.

Good practice of Intensive Interaction involves valuing and encouraging the participation, presence and control of the learner. Successful interaction can be achieved when we use our lifetime of experience and fluid ability to communicate, to support people who are socially isolated or who experience difficulty reading the behaviour of others. Intensive Interaction should involve pleasure and exploration of social consequences and aims to provide the emotional fulfilment which we all get from social connection.

References

Bates, E., Camaioni, L., & Volterra,V. (1975) The acquisition of performatives prior to speech *Merril-Palmer Quarterly* 21 (3), 205-226

Bates, E., Benigni, L., Bretherton, I., Camaioni, L. and Volterra V. (1979) The Emergence of Symbols: *Cognition and communication in infancy.* New York: Academic Press

Bremner J.G., (1988; 1994) *Infancy* Oxford: Blackwell Ltd

Bruner, J.S. (1981) Social context of language acquisition Language and Communication 1, 155-178

Harding (1984), Acting with intention: A framework for examining the development of intention to communicate. In L.Feagens, C.Garvey, R. Golinkoff,, M.T.Greenberg, C. Harding& J.N. Bohannon (Eds) *The origins and growth of communication* (pp123-135) Norwood, NJ:Ablex

Hewett D (2011) personal communication

Nind, M & Kellett, M. (2002) , M & Kellett, M. (2002) 'Responding to individuals with severe learning difficulties and stereotyped behaviour: challenges for an inclusive era' *European Journal of Special Education*, 17 (3) 265-282

Samuel. J (2003) An evaluation of Intensive Interaction in community living settings for adults with profound learning disabilities (PhD Thesis; Oxford Doctoral Course in Clinical Psychology)

Stephenson, J. & Lightfoot, K. (1996). Intentional communication and graphic symbol use by students with severe intellectual disability. *International Journal of Disability, Development and Education*

About the author

Mark Barber is Leading Teacher at Bayside Special Developmental School in Melbourne. He worked in UK as a special educator for 20 years before moving to Australia, where he has introduced Intensive Interaction to more than 90 schools and services for learners with severe-profound intellectual disabilities. He coordinates Intensive Interaction Australia and is a key figure in the organization of the Intensive Interaction DownUnder Conferences