Back to Basics

by Rosemary Crossley

WE SHOULD NOT ACCEPT UTTERANCES PRODUCED IN CIRCUMSTANCES IN WHICH THERE IS LITTLE CHANCE THAT THE PURPORTED MESSAGE IS WHAT THE COMMUNICATION AID USER INTENDED.

I recently visited the United States, Germany and Italy, and met many people who were using communication aids with facilitation. As one would expect, these communication aid users ranged along the continuum from novice to experienced – the novices getting out a few words with difficulty, and the experienced communicating fluently in complex sentences. The amount of facilitation used also varied, ranging from full hand support to a touch on the shoulder. Again, such variation was to be expected and gave no cause for concern, particularly as some users were very close to independence in their use of communication aids and some people who had once used facilitation were now able to type independently. Even when maximum facilitation was required and communication was far from fluent, most communication aid users clearly owned their output, and indicated this in a whole host of ways - their concentration during message creation, their frustration with typos, their body language when giving their message, their pleasure in the completed message, their associated speech or actions. Regardless of how much help they had received, the message was theirs. While one might suggest ways of reducing support or adapting technology to further empower the aid user, the underlying interaction was a cause for congratulation, not concern. What did concern me greatly, however, were those interactions in which there was almost no chance of the output being what the non-speaker intended to say. I saw far too many of these in each country I visited.

Most of the worrying interactions involved letter boards. Typically these boards had no grid separating the letters and no MISTAKE or ERASE to allow users to correct themselves or their facilitators. During message construction the 'user' was held firmly at the hand or finger by a facilitator. In the worst instances the 'user's' hand moved quickly around the board, often touching several letters, while the 'user' looked in the opposite direction. After this continued for a minute or so in silence, the facilitator would speak a sentence as if it came from the 'user', who still showed no involvement.

THIS IS NOT FACILITATION. THIS IS MANIPULATION.

Saying that a communication aid 'user' is being manipulated in such situations does not mean that the user has no skills. I observed some of these people when they were communicating successfully, using different equipment in a very different manner – receiving minimal support, keeping their eyes on the keyboard, correcting mistakes. Others I facilitated myself while they used letter boards (to which I had added ERASE and sometimes a grid that prevented two letters being hit simultaneously). With less support, with insistence on eye contact with the board, and with feedback on each selection, these people were able to demonstrate that they did have spelling skills. In the time available I could not ascertain whether their skills could have allowed them to produce the lengthy messages which had been ascribed to them.

The first response to criticism of such unconvincing performances is generally "But 'Joe' uses peripheral vision, so there's nothing to worry about." First, many of the people I observed had

their heads at such an angle to their boards that seeing their boards, even with peripheral vision, was an impossibility. Second, in the absence of partner feedback and an ERASE strategy, even direct eye contact is not sufficient for accurate message transmission through a letter board.

FEEDBACK IS ESSENTIAL FOR SUCCESSFUL COMMUNICATION AID USE.

All of us rely on feedback to ascertain that we are getting our meaning across as we intend. For speakers, primary feedback comes when they hear the sound of their own voices — aural feedback. Speakers often correct, modify or expand their initial utterances before receiving any secondary feedback, that is, acknowledgement from their listeners. In writing or typing, the appearance of the text on page or screen provides visual feedback, allowing us to correct and adjust as necessary before passing on our messages. In both spoken and written communication, primary feedback not only allows us to correct any mistakes, it enables us to keep track of what we're saying.

Primary feedback is more important in written communication than in spoken communication, because written communication is slower and therefore the demands on short-term memory are greater. One has both to retain the whole message in memory and keep track of where one is up to in production of the message. To find out just how hard that is without feedback, try writing a letter in the dark, with multiple interruptions and distractions such as those found in any classroom or social gathering. The memory demands on people who use communication aids are enormous. Typical speakers utter 150-200 words per minute, rapid touch typists may type 80 wpm, a handwriter may write 40 wpm, Bob Williams can generate 30 wpm plus on his Liberator, Steven Hawking can generate 15 wpm on his lap-top, Anne McDonald can dictate 9 wpm on her letter board. Producing the equivalent of one minute's speech takes the typist 2 minutes, the writer 4 minutes, Bob Williams 5 minutes, Steven Hawking 10 minutes and Anne McDonald 17 minutes. To get an idea of what this means, speak into a tape recorder for a minute then come back fifteen minutes later and repeat exactly what you said previously, without hearing the tape again first.

People using speech output communication aids receive primary aural feedback. People using keyboards with displays or paper output receive primary visual feedback (providing they look at the display or output). People who use letter boards receive aural feedback only if their partners say the letters, words and sentences they spell aloud. They only receive visual feedback if their partners write down the letters they select where they can see them. People with poor eyesight need auditory or tactile feedback, either from their devices or from their communication partners. People who can see and who find auditory feedback disturbing either need devices with displays or need their facilitators to write down each word they spell. Don't think feedback is just for novice spellers or novice facilitators - it is essential for every communication aid user. Some years ago I was honoured to partner Bob Williams when he used a spelling board to give a workshop at a conference. Bob's eye contact is perfect and he can signal yes/no quickly and clearly. He used his index finger to point accurately and independently to letters and words on a large communication board. My job as his partner was to say each letter or word he selected softly. If I thought I could predict a word I would do so, saying my prediction softly. As long as I was correct in my reading Bob would keep on spelling. If I said the wrong thing or he mishit, he signalled 'no'. I would then say the immediately previous selection again, to confirm it, and he would continue from there.

Here is a short sentence written as someone like Bob might spell it, with the letters selected in upper case and partner feedback in lower case I i W w O o would L / I like T t O to G g O go T to A a U u S australia – I would like to go to Australia. In this example there were no mishits and

no miscalls. The speller nodded at each completion and when the whole sentence was spoken. Without such mutual feedback, the speller would have had no guarantee that the partner hadn't missed letters, and the partner could not have offered any word completions. Production of the sentence would have taken much longer – more than double the number of selections – and until the whole utterance was spoken neither person would have had any idea whether the message was being read correctly. In this example spoken feedback was sufficient, but if either person had been unused to remembering strings of letters and words it would have been necessary for the partner to write down each word.

I have frequently heard the partners of people who use letter boards call out each letter correctly but then lose the thread of the message and say something completely different from the sentence the user spelt. We need to remember that the memory demands on the partner are the same as those on the speller, and that they are increased when the speller requires facilitation, as the partner has to provide support as well as reading the letters selected and assembling and keeping track of the utterance. Partnering Anne McDonald is very different from partnering Bob Williams. Anne has to point with her fist, and often touches 2 letters at the same time. When she uses facilitation, she is always vulnerable to facilitator error – facilitators who don't provide appropriate support, or whose own muscle tone is variable. She has asymmetric tonic neck reflex (ATNR) which means that when she extends her arm to hit a letter, her head often involuntarily turns away, causing her to lose eye contact with her alphabet board. In that case, if her partner doesn't say each letter aloud, Anne has no idea where her fist has hit, much less what letter her partner thinks she's hit. For her to get out what she wants to say involves many erasures, even with familiar partners. Most communication aid users fall on the continuum between Bob and Anne in the accuracy of their selections. Regardless of where they fall ALL need constant feedback.

To demonstrate the need for feedback, use a computer with the display turned off or covered up, and type a sentence with one finger while someone watches. Ask them to say what you've typed at the end of the sentence. Then turn on the monitor and let them compare reality with their version. I have tried this as both typer and watcher. It is very hard to keep track for more than a few words at any speed faster than 20 words per minute. Many people have difficulty at less than 20 wpm. And that is with no mishits, with all the spaces in the right places, and without trying to facilitate at the same time.

Indeed a good test sentence is "The real way to confuse your partner is to omit spaces or to put them in randomly." It is also true. While spaces are not essential for correct message reception, they do make it easier, and may be very important for inexperienced partners or those with shaky literacy skills. Encourage their use. It is time for all people involved in facilitator training to take a stand and refuse to accept utterances created in circumstances in which there is little chance that the purported message is what the communication aid user intended. In doing so we will not be disrespectful to these communication aid users; rather we will be supporting their right to be heard. We will also not be disputing that these communication aid users have the skills and desire to communicate. Rather, we will be behaving as we would to a speaker who was battling a lot of interference — we will be making an honest acknowledgement of our concern that we're not getting the message right. In this case the interference is coming from a facilitator who doesn't know the basic pre-requisites for successful communication aid use.

PREREQUISITES FOR ACCEPTABLE COMMUNICATION AID USE

In using a letter board the pre-requisites for acceptability are an ERASE on the board and provision of constant partner feedback, whether written or spoken. In using a device with a display or paper output, good eye contact is a pre-requisite for acceptability unless the device or the facilitator says each word aloud. Good eye contact is also essential if handwritten feedback is provided. It is vital that all communication aid users are shown how to use ERASE or BACKSPACE and given practice in doing so, by having their facilitators make deliberate miscalls during training sessions.

CORRECTING BAD FACILITATION

In an instructional setting it's easy to correct facilitators who are not providing feedback. It's much harder to do so politely in a social setting. I hand out a small leaflet which starts "CONGRATULATIONS! It's a pleasure to meet you and see you using your communication aid" and continues "Here are some tips which may help you and your partners". The full text is available on the Facilitated Communication Institute home page. Please use it, changing the contact address as appropriate.

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Indicators of poor facilitated communication training programmes:

- Lack of facilitator feedback partners who do not give feedback during message construction
- Lack of communication aid user feedback users who do not correct their partners either because they have no means of doing so or have not been empowered to use the means they have
- Lack of eye contact communication aid users who are not looking at their displays or the printed output and facilitators who are not monitoring the users' eye contact
- Lack of any reduction of support communication aid users with their hands held more than a year after commencing an FCT programme
- Lack of any OT program/involvement aimed at improving hand function
- Lack of multiple communication partners users who remain dependent on just one or two facilitators more than a year after starting to use communication aids
- Lack of any communication aids apart from ABC boards and desktop computers
- Lack of quick communication strategies e.g. word/phrase boards, or whole messages programmed into electronic aids
- Lack of unfacilitated communication strategies such as wide-spaced yes/no or multiple choice boards
- Lack of communication aid use in the community and throughout the day

While there can certainly be good explanations for any lack in relation to a particular individual, finding multiple lacks should be a cause for concern and questions should be asked, especially if those lacks apply to multiple individuals, indicating a systemic problem rather than individual issues.

We thank Rosemary Crossley, who has kindly permitted us to use her article on our web-site.