

Using facilitated communication to improve communication aid access

by Rosemary Crossley

To facilitate is to make easier. In facilitated communication training the task of using a communication aid is made easier for a student with a severe communication impairment. The degree of facilitation needed varies from person to person, ranging from an encouraging hand on the shoulder to full support and shaping of a student's hand to enable isolation and extension of an index finger for pointing.

Facilitation differs from other hands-on teaching methods such as co-active movement and gradual guidance. Using co-active movement you might, for example, put your hands over a student's hands and help him to pull his trousers up. Co-active movements are performed by both student and teacher together and it does not matter if the teacher's movement is stronger than that of the student (at least not at the start of training). In co-active movement you lead the student through the movement, in facilitated communication you are setting up a situation that will allow the student's own movement to be functional. It is vital that the choices made be those of the aid user. The direction of the movement is controlled by the person being facilitated, not by the facilitator. The aid user's movements should be stronger than that of the facilitator, who gives the minimum assistance necessary.

Any student whose speech requires augmentation and whose hand skills are not adequate for them to achieve a level of expression matching their receptive language is a candidate for facilitated communication. Beware of putting the cart before the horse here – as assessment of students with severe expressive problems is so difficult, no student should be excluded from the teaching program on the basis of previous negative assessments. Often the teaching is a pre-requisite for accurate assessment. Always give the student the benefit of the doubt.

As facilitated communication training requires both some hand skills and the potential for improvement in those skills it is not usually the method of choice for people with severe physical impairments, who are offered scanning or coded systems instead. Facilitated communication training offers most to students who are ambulant, for whom an easily portable communication system that is accessed manually is necessary. To date successful users of facilitated communication include individuals diagnosed as intellectually impaired (including individuals with Down Syndrome), individuals diagnosed as autistic, and individuals with mild cerebral palsy. Regardless of diagnosis, all potential users present with impairment of motor skills which preclude use of handwriting or signing for more than the most basic communication, and which significantly impede their independent use of communication aids.

The immediate aim in using facilitated communication is to allow the aid user to make choices and to communicate in a way that has been impossible previously due to neuro-motor problems. Practice using a communication aid in a functional manner is encouraged, to increase the user's physical skills and self-confidence and reduce dependency. As the student's skills and confidence increase the amount of facilitation is reduced. The goal is for the student to be able to access the most appropriate communication aid(s) independently.

Common problems requiring facilitation

1. Poor eye-hand co-ordination:

The student makes selections impulsively, without looking, or without allowing enough time between movements to scan the display and locate the target.

It is vital to ensure that the student makes eye contact with the target before making a selection. Someone who points without looking is unlikely to hit the target, and someone who does not scan the available choices cannot make a meaningful choice. At first the facilitator may have to restrain the student from moving until he or she is looking at the target area. Where the student's head is actually turning away from the target the facilitator may need to physically assist in the maintenance of a midline, eyes down, position. If these restrictions are enforced consistently eye/hand co-ordination usually improves quite rapidly.

2. Low muscle tone:

The student's arm and hand are "floppy" or "heavy". There is difficulty raising the arm against gravity and muscles fatigue quickly.

The immediate remedy is to provide some kind of support. The form of support is adjusted to the aid user. Supports used include:

- A. the facilitator places hand under aid user's forearm
- B. the facilitator holds the user's sleeve or a wrist band
- C. the user grasps one end of a rod and the, facilitator holds the other end
- D. the communication display is positioned so that the user can rest his or her forearm on the table or a typist's support – this is the optimum solution, but only suits users with no other accessing problems and only works while the user is sitting at an appropriate table.

If muscle tone is very low the student will do best when the aid is positioned as low as possible, minimizing the arm lifting required. Such students are often more independent in aid use when they are standing up.

Low muscle tone cannot be cured, although it can be increased for short periods. However, it does often go with reduced muscle strength – people with low muscles tone may not be asked to do much, and may not participate in sport – and we can do something about that. The long term strategy which assists people with low muscle tone increase independence combines practice in aid use with an exercise, program for arms and shoulders.

3. High muscle tone:

The student's arm feels tense, and movements are often too forceful, either over-reaching the target or pushing the aid away.

Usually the harder the student tries to perform the more muscle tone increases. The arm may begin loose and gradually become rigid. This problem is often associated with impulsivity (see 10 below).

High muscle tone cannot be cured, but its effects can be alleviated. Remedies include:

- A. shaking the student's arm until it feels floppy
- B. pointing to a target close to the body between selections, so that the student's elbow is flexed between selections
- C. regular pauses to give the muscles a chance to relax

4. Index finger isolation and extension problems:

The student has difficulty in extending the first finger while holding back the other fingers. Users with this problem either points with all fingers extended or use the middle finger (which is the longest). Either method make accurate selection difficult.

This is a very common problem. If you can't isolate a finger you cannot point accurately to a small target, and this makes it difficult to use a keyboard or even to have many choices on your pictureboard. Remedies vary with the severity of the problem, and include:

- A. an occasional reminder to keep the other fingers back
- B. asking the aid user to hold a rod in the palm while pointing to encourage flexion of the unwanted fingers (sometimes this prompts a reflex grasp in which case the index finger will also flex and the aim will be defeated)
- C. physical molding of the student's hand by the facilitator (usually, only, done for a short period at the start of a teaching program). When holding the user's hand the facilitator must take care to avoid all contact with the user's index finger. Attempts to support the index finger with the facilitator's hand are counter-productive and should be avoided.
- D. physically restraining the unneeded fingers - a simple method is to use a snug fitting sock. Make a small hole in its toe for the index finger, pull the sock down firmly over the student's hand so that the other fingers are bent and hold it in place by a piece of ribbon or velcro fixed around the wrist- This is a short-term solution - if pointing does not improve within a month further therapy advice should be sought.

A curved or limp index finger may be too weak to push down a key, and may have to be splinted for a short time or a pointer may have to be substituted in the early stages of training. Meanwhile exercises such as pushing into a ball of clay will be suggested to extend and strengthen the finger. It is generally quite easy to achieve independent finger extension; the use of splints slows this down, and they are very much a last resort. Hand molding, too, should be used for only a short period after the initial assessment.

5. Perseveration:

The student makes a selection and continues hitting either that selection or adjacent selections inappropriately.

This is a very common problem, though in people with communication impairment it has often gone undiagnosed. The immediate remedy is to break the pattern and pull the student's hand back to the edge of the table after each selection. Gradually this movement pattern become automatic and students withdraw their own hands after each selection. Sometimes providing an alternate target between the student and the aid can assist in the development of the desired movement pattern (e.g. student makes selection 1, hits red dot on table, makes selection 2, hits red dot, makes selection 3, etc.).

Perseveration affects the use of communication aids and creates difficulties with assessment. People who have no speech are often given tests involving pointing, and these will not provide a fair assessment for a person who has perseveration.

6. Using both hands for a task only requiring one:

The student points to two items simultaneously and it is hard to be sure which item (if either) was actually desired.

Every effort should be made to discover which is the student's preferred hand and all one-handed tasks should be performed with this hand. It may be necessary to restrain the other hand for some time or to devise other strategies to keep it out of the way, e.g. student may put it in her pocket, use it to hold a clutch purse or even sit on it!

7. Tremor:

Tremor can either be a continuous tremor or an intension tremor, where the hand is stable while at rest but trembles when the person tries to do something (such as point).

Tremor is very difficult to remedy. In the short term, stabilizing the limb (either by the facilitator holding the student's wrist, or by the student holding one end of a rod held by the facilitator) will assist. A long term program may involve the wearing of wrist weights while using the hands or the performance of exercises as suggested by an O.T. or psysiotherapist. This does not work for everybody, however. Tremor is reduced by pointing against resistance, and is helped by a really firm backwards pressure on the wrist.

8. Radial/ulnar muscle instability

The muscle of forearm, wrist and hand exert unequal pull on the hand or fingers. Sometimes the index finger swerves to one side as the student goes to point, leading to unwanted selections. The most common problem is for the aid user's index finger to swing across in front of the other fingers. Often the hand also drops down from the wrist thus making the tip of the index finger invisible to its owner, who is then pointing blind.

Any remedy which restores the finger to view will help in the short term:

- A. the user points as though pretending to shoot with the index finger
- B. the user holds one end of a rod while the facilitator holds the other in such a way as to ensure that the user's hand does not drop or swing away from the target

C. the facilitator's hand is used to correct the user's wrist and hand position

An exercise program to strengthen the student's arm and hand muscles is usually necessary to achieve long-term improvement.

9. Initiation problems:

The student does not spontaneously reach out to the communication display.

Some people find it very difficult to initiate a movement. A tap on the shoulder may be necessary before they can get up from a chair. As one person spelled out, "I know what you want me to do, but I just can't get it to happen."

A verbal prompt may be all that is required to start communication, e.g. "Do you have something to say?" though in the earlier stages a physical prompt such as a touch on the elbow is often necessary. It is important that the communication display is always readily accessible, and that any spontaneous movement towards it is reinforced with a positive response.

10. Impulsivity:

The student moves too fast to produce considered responses – starts pointing at the answer before you've finished the question, or points quickly all over the board so that you don't know which item was meant.

This is frequently, but not necessarily, associated with poor eye/hand co-ordination and the remedy is similar. Slow the student down and refuse to allow any selections made without looking. Maintain a slight backwards pressure, so that the student is always having to push against your resistance to reach the communication display. (This is good practice with all facilitated students other than those with significantly lowered muscle tone, as the resistance has a stabilizing effect and reduces the chance of the communication partner unintentionally directing the user to a selection.) Pull the hand back after each selection.

11. Proximal Instability:

The student's shoulder and trunk position is unstable. Often an overarm pointing action, rather than the more controlled underarm action is used.

If you want accurate finger pointing you must have the shoulder, which is the origin of the arm movement, properly stabilized. People with muscle weakness often haven't got sufficient stability at the shoulder to allow accurate hand movements. There are a number of exercises that can strengthen shoulder muscles. In the short term firm pressure on the shoulder or on the outside of the upper arm may assist. Seating which encourages a stable, upright posture is also important.

12. Reduced Proprioception:

The student moves awkwardly, sometimes overshooting and sometimes overshooting the target.

Proprioception is the sense that lets us know where the parts of our bodies are in space. To make an accurate movement it is necessary to know where you are starting from and to get feedback from your body as the movement proceeds. Reduced proprioceptive feedback is hard to diagnose with certainty, especially in a person with severe communication impairments. Apparently purposeless movements such as rocking which increase proprioceptive feedback may indicate that an individual has reduced proprioception. Often diagnosis follows treatment – a client without obvious problems

improved her pointing significantly when she wore wrist weights. In lieu of any other obvious explanation it is presumed that the weights gave her more feedback on the position of her hand and arm. Anything that highlights arm and shoulder position will help weights, pressure, massage.

13. Lack of confidence:

While not itself a physical problem nervousness certainly affects physical performance. The most common symptom is reluctance to respond, often combined with lowered muscle tone and reduced eye contact. Encouragement and success are the most effective remedies.

Literacy

Facilitation in itself is not directly connected with typing or literacy. It is a means of teaching manual selection skills that can be used in any situation in which choice-making is needed – selecting a chocolate from a box, choosing an item from a menu, making choices in a supermarket, pointing to body parts on a doll, matching pictures, etc., etc. All of these activities require similar eye/hand skills. Nonetheless, many of the users of facilitated communication are using keyboards and this has been an exciting outcome of this program.

Most students in developed countries have had considerable exposure to written language if not to formal literacy teaching; however, expressive impairments have prevented any literacy skills they have acquired from being recognized. Sixteen-year-old Joe used a typewriter with facilitation to show that he could read and spell. His mother said "Now I know why he takes his father's paper every night!" Many teachers and parents report that students were showing an interest in written material - notices, books, papers, magazines, TV commercials – that they found inexplicable until the students found a means of expression, via facilitated communication training, which enabled them to reveal that they had acquired reading skills. For this reason it is important that students be given open-ended assessments when they enter a communication program and not be pre-judged on the basis of previous performance or labels.

Developing Skills in Communication by Spelling

Successful communication, in whatever mode, has three basic requirements.

First, the sender of the message must have the necessary skills. If the communication is via speech, for instance, the speaker must be able to attract the listener's attention, speak clearly and loudly enough to be heard, and have a vocabulary adequate for the message they want to get across.

Second, the receiver of the message must have the matching set of skills. If the communication is spoken the listener must pay attention, be able to hear (or lipread), and be able to understand the speaker's language.

Third, the total interaction must facilitate the passage of information. In spoken communication, adaptation to the environment may be necessary – you stand closer to your partner and speak more loudly if there is a lot of background noise. The tone of voice and vocabulary have to match the situation as well as the message content. "Quick march!" on the parade ground will generally have a different intonation from "Hurry up." addressed to a child, though the two messages have a similar intention.

These three requirements apply to non-speech communication as much as to spoken communication; however, fulfilling the requirements in non-speech communication is often difficult. We learned our sending, receiving and interactive skills for social communication when

we were very young, and because of this we had two advantages – we were young and unpressured (nobody worried if we made 'mistakes') and we were immersed in a learning environment. Everyone we came into contact with, apart from other infants, had expressive language skills, an automatically provided us with appropriate models and reinforcements.

A person starting to use non-speech communication as an older child or adult is in a very different situation. We tend to be more judgemental of people as they (and we) get older, and the learner is likely to be aware of this and have a well-developed fear of failure. In addition, the learner is not immersed in a learning environment - almost the reverse. The people with whom the learner comes in contact may be unfamiliar with the whole notion of non-speech communication and are likely to be learning to use the learner's new communication aid or system at the same time he/she is. Correspondingly, the receivers require as much teaching as the learner does. We are frequently asked why 'Joe' doesn't communicate as well outside the therapy setting as he does at the clinic. Generally the answer relates to requirements two and three – the receiver's skills and the interactive strategies used – as much as it does to Joe's lack of confidence in using his new skills and equipment outside the 'protected' therapy situation.

Because the only way communication aid users can communicate exactly what they want to say, in the words they want to use, is by spelling, every effort is made to develop spelling skills in users of facilitated communication. Often spelling will be used in conjunction with another communication mode, such as word or symbol displays, to increase speed, but the spelling is vital for true, freedom of expression.

If Joe is just starting to use spelling for communication there is a hierarchy of activities which can be used to develop the access and spelling skills (and confidence) Joe needs for free communication, while at the same time Joe's communication partners develop their receiving and interactive skills in what is a new situation for everyone.

This is not a rigid structure to be proceeded through step by step. People may do a range of activities in the same session, they may never do some of the activities, and they may be doing highly structured activities with one partner and communicating relatively freely with another. If an attempt at interaction at one level fails, dropping back a level or two may well succeed.

Once initial success is achieved individuals are encouraged to extend their range of activities, regardless of the amount of physical facilitation (if any) they are receiving. Some aid users are communicating freely and fluently while still receiving wrist support. Others require no physical facilitation but still need to build their skills and confidence by rote spelling tasks. Equally, it does if the aid used is an alphabet board or a computer, the skills required are similar.

When the level of physical support is reduced it is often a good idea to go back to a more structured activity, one, in which the person is confident of success. A general rule, in fact, is that if the pressure on the person typing is increased in any way – new staff, spectators, reduced facilitation, ill-health, whatever – reduce the level of task in order to maintain success. As the communication impairments of many people are worsened by their lack of self-confidence the aim is always to set the aid user up for success and not to expose, them to any avoidable failures.

It is important that the content of the activity be varied to suit the age and interests of the person a child may enjoy a crossword about toys, a young man one about cars and a young woman one about pop stars. Each person requires the same degree of structure – the content and level of difficulty can still vary.

Activities Leading to Free Communication by Spelling

↑	Self-initiated conversation, where the users get aid or ask for it without any prompt.
↑	Spontaneous conversation, where the topic is chosen by the user.
↑	Wide-ranging conversation (encouragement to use a range of sentence structure may still be necessary: "Now you ask me a question.>").
↑	Answering questions – "What did you do at the weekend?" or "How did you like the movie?"
↑	Typing sentences in a set context – picture captions, describing pictures, speech balloons for cartoons.
↑	Exercises with a limited range of answers – "Give me a word that rhymes with 'day'", or "Give me the opposite of 'big'", or the game 'Elephant'.
↑	Completing common sentences or phrases – "Fish and _____" or "Too many cooks spoil _____"
↑	Cloze exercises – "Putting the missing word in the sentence, Bob _____ a car."
↑	Exercises with set answers known to the receiver – crosswords, general knowledge questions, names of friends or family.
↑	Typing set words – "Spell 'horse'.", or labelling household items or pictures.
↑	Copy typing – "The quick brown fox jumps over the lazy dog."
↑	Replacing missing letters in words – perhaps on the Talking Lesson One or Speak and Spell computer toys.
↑	Word matching – bingo, lotto, word association games (group activity only).
↑	Yes/no, true/false, and multiple choices – simple quizzes, "Do dogs go meow?", Type C if you want coffee and T if you want tea."

This list of activities is concerned solely with the development of spelt communication. It is not a complete list of communication behaviors. It ignores body language and eye contact, for instance, two vital communication skills we need to monitor in ourselves and our students.

Reducing Support – Increasing Independence

Facilitated communication training is used with people with severe communication impairments who are not yet able to access a communication aid independently but for whom independent direct access using their hands is a realistic and desirable goal. It is part of a process and not an end in itself.

Communication aid users may initially need physical assistance from their communication partners while they develop such specific skills as index finger isolation. As the aid users' skills increase the amount of physical assistance they receive should diminish. The ultimate aim is for the users to access their communication aids with no physical contact from their communication partners.

This aim is not always achieved. There will always be some people who commence facilitated communication training but find that even after considerable training independent aid access is still impossible, or at least still so slow and arduous as to severely limit their communication. These people need their communication strategies reviewed. They may change to indirect access (using a scanning system), they may continue with direct access in another modality (eye-pointing, for instance) or they may elect to remain facilitated, perhaps being independent in some situations and not others. This group is a minority, however, and the presumption when starting facilitated communication training should be that the user will eventually move on to independent access.

To ensure that users do not become overly dependent on their facilitators it is important that all facilitators are aware from the start that independence is the goal. It is also important that attempts are made to fade support as soon as a person starts to use a communication aid successfully with facilitation.

The first step in reducing dependency is for all communication partners to give the minimum support required for communication to succeed. The second step is to ensure that the aid user communicates with as many different partners as possible. In order to fade support successfully it is necessary to know what problem or problems the individual had that meant they had to be facilitated in the first place.

Some problems are remedied directly by the facilitation process. Eye/hand co-ordination problems, for example, usually improve quite rapidly if facilitators consistently refuse to allow aid users to make a selection unless they are looking at their aid. In this case it is easy for facilitators to monitor improvement in users. Facilitators record the number of times each aid user has to be reminded to bring his or her eyes back to the task in a five minute period. As soon as it is routine for a user to get through five minutes without a reminder physical contact should be withdrawn as quickly as is possible without the aid user regressing. Spoken prompts may initially be needed as a substitute.

Other problems may require other therapy in addition to the communication sessions themselves, or may require the aid user to learn special strategies. Low muscle tone and weak fingers require specific exercise routines or adaptations in daily activities to build up muscle strength. Some aid users who have difficulty isolating an index finger may be able to type without hand support when holding a pen in the palm of the typing hand with their other fingers. People who have difficulties with perseveration may be helped by learning to hit a dot on the table after they type each letter.

Other factors may also affect independence. Some people have variable muscle tone, and may be able to type independently one day but not the next. Some people are independent in familiar surroundings with familiar people, but out in public become nervous and seek support. It is important to provide the temporary support needed in these situations. Not only does the individual have a right to communicate, the nervousness is only going to be cured by an increase in

confidence, and this is unlikely to occur if the person experiences communication failure or frustration every time they're out in public.

Environment is an important factor in independence. A person with a tremor is not going to be helped by sitting on a chair that won't let their feet reach the floor. A person with low muscle tone is far more likely to be independent if the communication aid is positioned as low as possible, to minimize lifting against gravity. A person who is visually distractible will require less prompts to keep their eyes on task if they facing a wall rather than a window looking on to a busy corridor.

There is a continuum in the provision of facilitation, running roughly through:

1. hand holding
2. rod (user holds rod while facilitator holds other end)
3. wrist support
4. forearm support
5. sleeve or elbow support
6. upper arm support
7. shoulder pressure
8. shoulder touch
9. physical contact with another part of the user's body.

Each person starting facilitated communication training needs a different level of support. It is important that everyone working with an individual is made aware of his/her particular support needs, and that no one provides more support than the minimum required. Where there are a number of aid users requiring facilitation it is understandably common for staff to adopt a lowest common denominator approach, with all trainees being offered the level of facilitation required by the most dependent because that is guaranteed to succeed with everyone. Such an approach will also guarantee continued dependence. If fading is to succeed it has to be individualized, has to be applied consistently, and has to start from each individual's baseline level of support.

Dependency may be related to aid and position. Many people with low muscle tone are initially more independent standing up, when they don't have to raise their arms against gravity. Such people may be independent on devices with small keyboards (such as the Canon Communicator) but still require some support when using a larger keyboard on a computer or typewriter. Some individuals can type without physical contact if their partners hold the communication aid low (and in this situation the partners' direct involvement may also provide emotional support and encouragement).

While independent aid access is worthwhile even if it can be achieved only in certain situations, and while this situational independence may be useful in validating a persons' communication, the ultimate goal for all aid users should be the kind of independence that allows them to access all their communication aids in the most convenient manner. In the main this will be while the aids are on an appropriate height table. Correspondingly, during the period of fading support it is important to record at each stage the aid or aids that were used, the position of aid, and the position of the individual – "shoulder touch when seated with Canon Communicator held low", for example – so that meaningful comparisons and evaluations of progress can be made. In order to monitor progress in increasing user independence it is essential to maintain full records. The records will not only encourage continuance of the program but also identify plateaus or problems so that help can be sought.

The aim of every augmentative communication program is for the trainees involved to communicate with those around them as fluently and independently as possible. A reduction of support often results in a loss of speed and accuracy, at least initially. It is important to ensure that trainees understand the aims of the program. Trainees should never be made to feel that fading is a test, and that they have failed if it doesn't work out. Jane, for example, has low muscle tone, and types well with just a touch on her shoulder. She soon tires, however, and starts making many mistakes. When this happens her facilitator offers her more support so she, can finish what she wanted to say. Withdrawal of support should be a flexible process and aid users should feel secure in the knowledge that they will never be left unable to communicate.

Independent communication is the best kind of communication, but even the worst kind of communication is much better than no communication at all. Independence is a valuable skill; communication is a basic human right.

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