

Record

141

File Number

10113

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Title: Controversy over facilitated communication: Severe communication impairment

Original source: TASH Newsletter Volume 19 Issue 5

Resource type: Written

Publication Date: 01/05/93

Publisher info: TASH

Abstract

Doug Biklen, Director of the Facilitated Communication Institute at Syracuse University, USA, explains facilitated communication, an alternative to speech for many people who do not speak or whose speech is highly limited. He discusses, in 2 articles, the complications which may arise and why, including the fact that it is usually the first time people using the system have had their communication monitored. Biklen discusses the recent controversies over allegations of abuse made by people using the system and the challenges inherent in such claims to existing educational, legal and social support systems. **Keyword: Self determination**

CONTROVERSY OVER FACILITATED COMMUNICATION

by Doug Biklen

Facilitated communication is an alternative to speech that can be useful for many people who do not speak or whose speech is highly limited (e.g. echoed, repetitive, limited to one, two or three word utterances) and who cannot point independently and reliably. It involves typing with a single finger while being supported by a facilitator/communication partner. The support may include help in isolating the index finger, stabilising the arm, backward resistance and slowing down the person as he or she points, pulling back after each selection, or just a light touch at the elbow or shoulder or other location, depending on the specific physical problems that impede independent, reliable pointing. The goal of independent typing or pointing should be realisable for most individuals who learn to communicate with facilitation.

While the method seems quite simple, it can be complicated, for example if a person mixes intentional and echoed words in typing, if a person has word finding difficulties, if a person lacks confidence, if facilitators fail to ask clarifying questions when appropriate, if facilitators overinterpret an individual's typing, or if facilitators ignore important aspects of the method such as giving the least amount of physical support needed and monitoring to ensure that individuals look at the keyboard or other target. Another complicating factor is the content of what people may type. People may express thoughts that others would rather not hear or which are confusing.

It is also very important to remember that for most individuals using facilitated communication, this marks the first time that they have had their communication monitored (i.e. heard and responded to). Let me give an example. Recently, a teenager typed a page and a half description of how he had hit his teaching assistant/facilitator; his speech teacher facilitated him as he explained the incident. He said he was angry that he had to depend on this person to speak the words that he typed. We knew that these were the student's own words because he had typed out a similar statement with another teacher as his facilitator, expressing frustration at not being able to speak and of anger toward the teaching assistant/facilitator who can speak. But, when we checked on the hitting incident, we learned that it never happened. Rather, the teenager later explained, he had only been thinking about such a scenario. Well, of course we all think about such things, if not about hitting someone then perhaps about yelling at, scolding, or arguing with someone, but most of us have learned not to state such thoughts as having actually happened. This student had not yet learned the importance of clearly separating expressions of what has happened from what has merely been thought about, considered, or imagined. Presumably, because this student does not have a history of having his communication monitored, he has not learned this lesson. He will have to

learn it now. At the same time, he has reported accurately on other matters and he has passed numerous messages that we were able to validate.

As long as this student was talking about hitting someone else, his account posed no great challenge to himself or to the people around him. They could all discuss it and work it through. But imagine if he had instead reported that he had been hit. Then the statement might well have evoked a formal investigation by legal authorities. In fact, I have described such an incident in my book, *Communication Unbound*. Another teenager reported that his father had hit him, but he did so only in response to leading questions. When asked about it, he reported to authorities that he accused his father of hitting him because he thought a particular facilitator wanted him to say that; the facilitator had been asking 'Did your father hit you?' The only instance of being hit that he could give was of his father slapping his hands when he had pulled his sister's hair.

Recently, facilitated communication has come into the news amidst controversy over allegations of abuse levelled by individuals who are using facilitated communication to express themselves. Some of the allegations have led to the accused confessing abuse. Some of the allegations have led to physical examinations of the complainants, showing in several instances clear physical evidence of abuse. And some of the allegations have been either unprovable or concocted. The first allegation that we became aware of was made in April 1990 by a female student who had been using facilitation for only three months and whose typing skills were limited mainly to single word expressions. She disclosed that a teaching assistant had touched her inappropriately; there were witnesses and the teaching assistant confessed. The assistant plead guilty to a misdemeanour sex abuse charge and was placed on probation with the condition he cease working with children. In the one case that we know of in which facilitation was allowed in the courtroom, a residential worker in Kansas was found guilty of fondling an 11 year-old boy (*Wichita Eagle*, March 31, 1993, p.1). In two cases in New York State, sex abuse allegations were never aired in court because the family court judges disallowed testimony given by facilitation, arguing that the method had not yet been accepted in the scientific community. Some critics of facilitated communication have suggested that abuse allegations given by people who use facilitation are perhaps the products of witting or unwitting influence by facilitators; that is, they are the facilitators' thoughts and not those of the individuals with the communication disability.

Clearly, any allegation of abuse is a serious matter with serious consequences. And allegations of abuse, investigations of abuse, and prosecution of abuse are generally very complex, as witnessed by the many such cases involving non disabled, speaking people in the news nearly every day. There is no reason to believe that such matters would be less complex when they involve people who use facilitated communication as their means of expression. And in fact there are several additional, potentially complicating factors such as automatic or echoed language and word finding problems to consider. Most important, any attempt to address allegations of abuse, whether made by people who can speak or by people who communicated with alternative or augmentative systems, demands thoughtfulness.

When we became aware of such abuse allegations by people who use facilitation to express themselves, we developed a statement to help parents, professionals, and legal authorities understand allegations of abuse that are made by people using the facilitated communication method. That statement is reprinted on page 4; this statement and supporting appendices, including an explanation of word retrieval problems and bibliography, are available from the Facilitated Communication Institute at Syracuse University (364 Huntington Hall, Syracuse, NY 13244-2340) at a charge of \$3.00.

Severe Communication Impairment, Facilitated Communication, and Disclosures of Abuse

by Chris Borthwick, Missy Morton, Doug Biklen & Rosemary Crossley

Severe Communication Impairment

A large number of children and adults with diagnoses such as intellectual impairment, autism, or severe cerebral palsy have no usable speech and cannot use sign language. People who are unable to communicate are obviously at increased risk of abuse.

Facilitated Communication Training

Facilitated communication training is an educational technique intended to allow people who cannot speak or sign to access communication devices. One person (the facilitator) provides support to the arm, wrist or hand of another person who is thus enabled to control their pointing sufficiently to point to pictures, words or letters. Support should be faded back as non-speaking persons improve their pointing. The ultimate aim is independent communication, but the need for support may persist for many years.

People with severe communication impairment have previously been thought to be unable to communicate because their intellect was insufficiently developed. The conclusion being drawn from the reported successes achieved through facilitated training is that these people have neurological defects of the same kind as those enumerated in post-trauma cases - apraxia (motor planning problems), aphasia (word-finding problems), disinhibition, and problems with initiation and perseveration - that do not necessarily affect their ability to process information and which can be evaded in whole or in part through accessing a different output channel. Once offered the opportunity many students with a variety of diagnoses have been able to demonstrate unexpected literacy and numeracy skills concealed by such things as poor motor skills and motor planning problems.

Giving a voice to a group of people who have long been silenced challenges many of our preconceived notions about what kinds of needs they have and how we should meet them. Having a voice also means that people are able to speak out about what has happened to them in the past, and many people have used

their new ability to communicate to make statements about past and present abuse. Many such incidents have already reached the reporting system, more are reported each week, and as the use of this method spreads such disclosures will become still more common. Some can be confirmed by independent evidence, some cannot be; some may not be accurate. All require serious attention.

Allegations of abuse can present difficulties even when accusations are made by people who can speak and are of full age. Accusations made with facilitation encounter these difficulties and present others of their own. They provide many challenges to existing educational, legal, and social support systems.

Disclosures of Abuse through Facilitation

Dealing with complaints made through facilitated communication may be seen as a series of decision points. At each point it is necessary to consider:

- a) what decisions must be made;
- b) who should make the decision; and
- c) what decision-making processes would be appropriate, including
 - i) what considerations should be taken into account, and
 - ii) what persons or bodies should be consulted?

At each stage, the person who has responsibility for the decision must both consider the problems that emerge for the first time at that stage and review what has been done at all the stages that have gone before. At each stage, also, the person will require counselling and support.

"Can the person communicate through facilitation?"

The facilitator has followed recommended communication practices, as set out in the literature and the person has apparently spelled out messages.

It is possible to be mistaken about this, and once the training is under way it is important to confirm at some stage that the method is working as intended. This can be done through incidental message passing (where a person reveals information that others can verify but which was not known to the facilitator), through idiosyncratic language use (where a person uses the same idioms or spellings with several facilitators), or through having two facilitators independently receive the same message. If this hasn't yet been possible - where, for example, the person's first message is about abuse - something like it may have to be done at a later stage.

Other laboratory-based tests involving such methodologies as shielding the facilitator with earphones have been proposed. Because of the continuing problems that these people have with initiation, motor planning, and word finding under pressure, such tests are seldom appropriate or successful. Such tests do not adequately provide for the effects of the disabilities such as apraxia, aphasia, and disinhibition that have till now been masked from us by the assumption of retardation. These disabilities not only render existing tests inoperable but place immense difficulties in the path of any formal testing.

Message-passing is often the best available test, although even then allowances may have to be made for people with word-finding problems who can give a message in general terms but not in its exact words.

"Has an allegation actually been made?"

The facilitator has received a message through facilitated communication that seems to relate to abuse.

Allegations of abuse have to be reported; all states now have mandatory reporting requirements, and facilitators should make themselves familiar with the requirements of their own state's legislation. It isn't the business of the facilitator to decide whether the allegation is true, or even if it's credible; it is important, however, to make sure that what the person actually wants to say is in fact an allegation. Facilitated communication is never as fast or as fluent as normal speech. Messages tend to be short, even telegraphic, and may omit grammatical bridges. It is not always clear what message the person is trying to get across with the words he or she has spelled out.

- *The message may be incomplete;* One person spelled out MY FATHER IS FUCKING ME - clear enough, you would think, if the facilitator hadn't carried on to get MY FATHER IS FUCKING ME AROUND.
- *The message may be telegraphic;* One person spelled MY FATHER FUCKING CUNT and meant MY FATHER IS A FUCKING CUNT.
- *The message may be inherently ambiguous;* One person spelled MOMSEXBOYFRIEND ME, which can be read either MOM SEX BOY FRIEND ME or MOMS EX-BOYFRIEND ME. These are different messages (and neither of them is clear).
- *The letters or words chosen may not be those that the student really intended;* The person may have word-finding problems. Difficulties with word-finding do not necessarily affect understanding or processing of spoken or written material, but can mean that the person is unable to think of the right word for what he or she wants to say and has to give another related word instead. Care must be taken that asking of clarifying questions does not turn the receiving of a disclosure into the kind of interview more appropriately conducted by law enforcement investigators. It is impossible to lay down firm rules, but facilitators should be aware of the possible complexities involved. It is also essential that clarifying questions are not leading questions and do not suggest what the person's response should be. In several cases what have seemed to be allegations of abuse have in fact been the result of people with communication impairments answering 'yes' to leading questions. One disturbed student with self-administered bruises was asked "Your dad hit you, didn't he? Why did he hit you?" When he answered "yes" there was an investigation. The police determined that no such abuse had taken place, and that he had merely been giving an inappropriate response to a series of leading questions.

- *The student's knowledge of the vocabulary may be defective.* One Australian student typed out that a policeman had raped her mother. On questioning it turned out that Lyn thought 'raped' meant the same thing as 'flirted with'. (Such a usage should, of course, give rise to further inquiry.)
- *The investigator has received a report of an allegation of abuse.* One facilitator can in any given case be mistaken, or can be influencing the person, and as a precaution it is helpful to have the message repeated to a second facilitator. If this is not immediately feasible a decision has to be taken as to whether the situation will allow any decision to wait until a second facilitator can be introduced. If with a second facilitator the message is confirmed in detail then it may be taken as confirmed that an allegation has been made.

"Is the allegation credible?"

The investigator has decided that an allegation has genuinely been made.

The protective agency must apply the same standards to the case as it would apply to any other case. It must neither down play the testimony nor treat it as somehow more reliable because it is in print. It must be emphasised that validation of the communication does not mean validation of the allegation. Many people accept that because an allegation has been typed is true, and, as a corollary, believe that, if it turns out not to be true, then that means that the person didn't type it. People who can type can also - sometimes - lie or make mistakes, just like other people.

The slowness of facilitated communication presents obvious problems in investigating a complaint. Someone using facilitated communication may be able to type 150 words in an hour, and may only be able to work for a few hours each day. This would be the equivalent of only a few minutes speech, and it may take some time to get a quantity of data together for examination.

"Does the allegation appear to be true?"

The investigator has carried out an investigation and collected all available evidence.

Some persons making allegations have been able to provide supporting information that confirmed their account. Some persons have supporting witnesses; one case in a Syracuse school was also reported by some of the person's schoolmates, and the perpetrator made and signed a confession. Some other evidence can be collected by normal investigative means; in one case the boy and the alleged abuser were suffering from the same sexually transmitted disease. In cases where the person's statements have to stand alone then its credibility must be assessed by normal standards.

"How should the case be handled?"

The prosecutor has received a report suggesting that there is evidence of abuse.

As the questions above show, there are going to be obvious evidentiary problems. There will also probably be problems to do with the limited life experiences of these people. They may well have used only a few thousand

words in their lives to date, an allowance that would last an ordinary person a week. Their communication training will have been conducted in an atmosphere of encouragement and acceptance, and their communication may well deteriorate considerably under pressure. If the facilitator increases support to compensate for the greater difficulty this may lead to other problems.

Even if it has been established (by say, message-passing between two facilitators) that the person with communication impairment can communicate, and even if it has been established also (by the use of several facilitators) that the person did make the allegation, it still remains hypothetically possible that a facilitator could still influence the output of the person in subsequent communication. There is no way to monitor a facilitator's work in a particular situation while it is going on. This is an inherent feature of the use of the method, and in this respect FCT resembles the use of an idiosyncratic sign language system.

The reporting of abuse through facilitated communication has already allowed many people with communication impairment to challenge their exploitation. The process of establishing abuse is complicated and challenging, and if proper procedures are not followed the outcomes may be confused and unsatisfactory. If done correctly, however, facilitated communication training has the potential to be an immensely powerful tool for people who until now have been denied the protections others take for granted.

This article and statement were prepared by the Facilitated Communication Institute at Syracuse University. The Facilitated Communication Institute is associated with the Center on Human Policy. Doug Biklen, Director of the Institute, has had a long association with the Center on Human Policy's Research and Training Center on Community Integration. The opinions expressed herein are solely those of the authors and no endorsement by the US Department of Education should be inferred. Space in the Newsletter is provided under a subcontract with TASH.