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Facilitated Communication Outcomes

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Short Abstract

As the first individuals to commence typing with facilitation complete tertiary education it is evident that the outcomes of facilitated communication are important and cannot be ignored. This presentation will examine both the negative and the positive outcomes of facilitated communication, and attempt to elucidate factors necessary for success.

Proceedings

Facilitated communication training was first introduced to ISAAC (International Society for Augmentative and Alternative Communication) in a 1988 conference paper entitled "Unexpected communication attainments by persons diagnosed as autistic and intellectually impaired" (Crossley, 1988). Since then facilitated communication (known in the US as FC and in Australia as FCT) may have attracted more media attention than any other AAC¹ technique (Augmentative and Alternative Communication). It has been reviled and lauded. In some areas it is banned; in others it is the intervention of choice for certain diagnostic groups.

More than ten years later, it is time to review the situation of FC, and examine its outcomes.

The initial 1988 paper concerned those individuals with diagnoses of autism and intellectual impairment of intellectual impairment with autistic tendencies who had attended three or more assessment and treatment sessions at DEAL Communication Centre during 1986-7 (n=34). Of these, most "had readily observable physical problems affecting hand function such as severely impaired eye-hand co-ordination, abnormal muscle tone (usually low, occasionally high) and disorders of initiation, inhibition and perseveration. Other more specific problems, including immature grasp, inability to isolate the index finger, shoulder girdle weakness and radial/ulnar muscle imbalance were often apparent during the interdisciplinary assessment procedure." (Crossley, 1988)

The paper described the strategies used to remedy these problems during assessment and through on-going therapy, and stated that 23 of the 34 were communication with caregivers and/or teachers by spelling sentences, of whom nine were able to type short utterances without facilitation. Apart from the need for facilitation, the individuals showed various difficulties with written conversation, including word-finding and auditory memory problems, lack of awareness of conversational conventions and extreme egocentricity in their choice of conversation topics. (Crossley, 1988)

¹ Augmentative and Alternative Communication.

In facilitated communication a partner or facilitator makes it easier for a non-speaker to access a communication aid by providing structured physical support. In facilitated communication *training* this support is combined with exercises designed to improve the communication aid user's hand use, with the aim of enabling him or her to use communication aids independently. (Crossley, 1994)

Facilitated communication training was never problem-free. The most obvious concerns were the need for facilitation, the dependency that this could produce, and the risk of facilitators unduly influencing communication. Essentially facilitated communication training was an ad hoc solution to some of the communication problems of ambulant school-age children or adults with both severe speech and hand function impairments whose communication could not be put on hold while they undertook a lengthy occupational therapy program. (Crossley, 1992) It excited attention because the communication produced with facilitation was unexpected in both style and content, and challenged previous assumptions about the language skills of specific groups, especially people with autism (Biklen, 1990). It aroused controversy when people who typed with facilitation complained about their treatment, especially when some of these people failed tests designed to resolve questions of authorship (Cummins & Prior, 1992).

The flood of articles on FC after 1990 can be divided into three groups – instructional and theoretical pieces (such as Duchan, 1993), qualitative research and case studies (such as Biklen & Schubert, 1991), and quantitative research and test results (such as Wheeler et al., 1993). The qualitative articles have been predominantly positive and the quantitative articles have been predominantly negative. The extent and virulence of the controversy in the early nineties was extraordinary (Cardinal, 1994).

Facilitated communication was a topic at the 1994 ISAAC research symposium. The session chair, Steven Calculator, commented that no other communication strategy, or its users, had ever been subjected to a similar scrutiny. Calculator wondered what would have happened to other augmentative communication strategies if they and their users had been tested to such an extent in the early days of AAC.

Five years later both the early enthusiasm and the later criticism have both reduced, leaving behind a collection of resolutions and position statements framed by professional bodies and disability groups in the heat of the controversy. (Crossley, 1997) Also left behind are the individuals who used communication aids with facilitation in the early nineties. Because of the negative publicity and continuing controversy, many no longer have access to facilitation, or indeed to any AAC. Recently an adult centre in Melbourne sold ten communication aids which had been locked away since the height of the controversy. Their users had included some of the individuals reported as developing independent typing in Crossley's 1988 paper or Biklen's 1990 article. These people had not failed tests – they were barred from using their communication aids after several local psychologists criticised FC in the media (Crossley, 1997).

All families and agencies were not deterred by the controversy, however, and the results being achieved by those who have continued to use FC raise important questions for all AAC practitioners.

Beukelman and Mirenda describe one long-term user in the section on facilitated communication in the 1998 edition of their widely-used textbook

"Sharisa Kochmeister is a person with autism who at one time had a measured IQ score somewhere between 10 and 15 ... She does not speak. When she first began using facilitated communication (FC) several years ago to type on a keyboard, she required an FC

facilitator to hold her hand or arm as she hunted for letters on a keyboard. No one thought she could read, write, or spell. She can now type independently (i.e., with no physical support) on a computer or typewriter.

Sharisa joins a small group of people around the world who began communicating through FC and are now able to type either independently or with minimal, hand-on-shoulder support. There can be no doubt that, for them, FC "worked," in that it opened the door to communication for the first time. In addition, hundreds (or even thousands) of individuals use FC with physical support. To many observers, it does not seem clear whether or not these individuals are authoring their own messages. Thus, FC has become controversial and hotly contested as a valid and reliable technique... We include FC here because of Sharisa ... and others who now communicate fluently and independently, thanks to FC. For them, the controversy has ended." (Beukelman & Mirenda, 1998, 327)

After describing FC and the controversy, Beukelman and Mirenda discuss the pros and cons of its use before giving Sharisa the last word:

"I HAVE A VOICE NOW – THEY WILL NOT RETURN ME TO PRISON. THEY WOULD NOT DO THIS TO HELEN KELLER AND SURVIVE UNSCATHED , THEY WILL NOT DO IT TO US, EITHER. IT'S OUR TURN NOW. (Typed independently by Sharisa Kockmeister, age 15, at a press conference in response to a television show criticizing FC, 1994)" (ibid 329). In 1999 Sharisa Kochmeister was a successful college student.

The negative studies of the early nineties stimulated research into the factors that affect test success for people using facilitation, including the nature of the tasks set, the training of facilitators and aid users, and their experience in undertaking tests. This research showed that the test outcomes were predictable. Studies such as that conducted by Cardinal et al. (1996) in which student were allowed to develop competency in taking tests and to practice the skills required produced a high proportion of successes: studies which did not allow any practice produced almost one hundred percent failures (Biklen & Cardinal, 1997).

Many issues remain. The percentage of FC users who can be expected to achieve independent communication aid access is not established. The neurological impairments underlying many of the observed hand function impairments await elucidation. Facilitator training is often of dubious quality, despite the effort of various agencies in trying to establish curricula and best practices (Disability Program, 1997) and there is an immediate need to ensure the future access to communication of individuals who have not achieved independent communication aid use.

The paper "Unexpected communication attainments ..." concluded with a suggestion:

"In view of the extra difficulties added by this study to the existing problems inherent in the concepts of autism and intellectual disability it would seem essential to return to basic redefinition of this population. What is required is a new terminology that separates, as the terms 'autism' and 'intellectual disability' do not, observable physical characteristics from behavioural interactions, and which avoids as far as possible basing assessments on assumptions as to the cognitive significance of levels of social functioning or physical skills." (Crossley, 1988)

One of the paper's subjects was Lucy Blackman, then aged 15, who had been diagnosed as autistic and labelled significantly intellectually impaired. Lucy is now able to type independently. She has graduated with honours from Deakin University and recently published her first book (Blackman, 1999).

The outcomes of facilitated communication are important and cannot be ignored. This presentation will examine both the negative and positive outcomes of facilitated communication, and attempt to elucidate those factors necessary for success.

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