
Ethical Issues Related to the Use of Facilitated Communication Techniques with Persons with Autism

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Abstract

The use of Facilitated Communication techniques recently introduced and now widely used with persons with autism poses a number of ethical dilemmas for psychologists. These dilemmas stem from the lack of empirical support for the validity of messages communicated with facilitation. Using the *CPA Code of Ethics for Psychologists* (1991) as a guide, this paper will highlight a number of ethical issues pertinent to psychologists working with clients who use Facilitated Communication techniques.

In the past few years, the use of Facilitated Communication techniques (F/C) with autistic individuals has become a topic of considerable controversy (Cummins & Prior, 1992; Prior & Cummins, 1992; Rimland, 1990). Facilitated Communication (F/C) involves the physical support of a person's arm, wrist or hand by a facilitator to enable them to use equipment such as electronic typewriters, computer keyboards, or alphabet and picture boards for purposes of communication. Much of the controversy stems from the fact that the validity of messages communicated when using a facilitator remains to be established empirically. Guided by the ethical principles outlined by the Canadian Psychological Association (1991), this paper will discuss the ethical dilemmas faced by psychologists working with clients and their

families or caregivers who use this mode of communication.

Since the introduction of F/C in Australia in 1988 by Rosemary Crossley, and then in the United States in 1990 by Douglas Biklen, there have been many reports of autistic individuals who were either mute or echolalic suddenly demonstrating literacy and numeracy skills with the use of facilitated communication (Rimland, 1990). F/C has challenged previous notions regarding the nature of autism, and as a result, has sparked new hope and enthusiasm for parents, caregivers and teachers of individuals with autism. However, the claims made by proponents of F/C also have prompted considerable controversy. Although, calls for controlled evaluations (Cummins & Prior, 1992; Minnes, 1992) have been resisted by proponents of the technique, increasing numbers of cases of alleged abuse communicated through F/C (Rimland, 1992) have resulted in a growing number of research studies.

Three major paradigms outlined by Schwartz and Jacobson (1993) have been used. In the first, questions are posed but facilitators do not have access to information presented to the person being facilitated. Auditory information may be altered through the use of earphones (Hudson, Melita & Arnold, 1993; Perry, Bryson & Bebko, 1993) or visual screening may be used to prevent facilitators from viewing stimulus materials or possible responses (Perry et al., 1993; Wheeler, Jacobson, Paglieri & Schwartz, 1993). In the vast majority of studies using such approaches, results uniformly indicate that correct responses to questions or correct naming of pictures or objects are rarely possible when the information is not available to the facilitator. Indeed, when subjects and facilitator are presented with different information, the typed responses most frequently are appropriate for the information

presented to the facilitator.

A second approach which has been seen to be less confrontational involves "message passing" (Perry, Bryson, & Bebkco, 1994). In this case, questions are asked about events or activities which have occurred or information presented in the absence of the facilitator, or the subject is merely asked to tell the facilitator about what happened while they were out of the room. The results of studies using this approach indicate that appropriate communications have occurred only in cases where the subject was able to type independently (Schwartz & Jacobson, 1993).

In a third approach known as a training model, gains in cognitive and language skills are measured as clients and facilitators are trained. While increasing skill in F/C has been documented in these studies, comparable gains in the ability to name objects or letters or to recognize words have not been found (Schwartz & Jacobson, 1993).

To date, over 30 studies have been conducted using a variety of these evaluation techniques (Green, 1994). While reports of highly sophisticated communications through facilitation abound, reports of individuals who use F/C achieving complete independence in their communication efforts are very scarce, and the results of well controlled studies strongly suggest that facilitators are unwittingly or unconsciously influencing the communications being typed (Hudson et al., 1993; Rimland, 1992; Wheeler et al., 1993). In the few cases where some indication of independent communications has been reported, it is important to note that only minimal naming responses and usually only one word answers were involved, or that the individual was able to type independently before learning facilitated communication techniques (Perry et al., 1994).

Despite the increasing number of scientific studies of F/C which do not provide evidence supporting the validity or independence of messages communicated with facilitation (Rimland, 1993), the use of F/C techniques continues to spread across North America. Thousands of parents, teachers and others

have been trained as facilitators and F/C has been adopted by many school boards and agencies.

Given the lack of empirical data supporting the validity of this technique, a basic ethical issue for psychologists is whether they should be involved at all with such an approach. However, clinicians working with autistic individuals and their families face another ethical dilemma. If, on the one hand, they reject the technique outright, their relationship with the family and the client will be jeopardized, if not severed. On the other hand, if they participate in the use of such a technique, they may be breaching ethical principles. The outcome to date has been the development of serious rifts in relationships between professionals and parents or caregivers of autistic individuals, as well as between groups of professionals who are either believers or non-believers in F/C (Minnes, 1993). In an effort to bridge the gap between the two camps, this paper attempts to take an open-minded approach addressing ethical issues concerning both the benefits and risks involved in the use of F/C.

I RESPECT FOR THE DIGNITY OF PERSONS

The ethical principle of Respect for the Dignity of Persons highlights the expectation that all individuals have the right to be treated as people rather than as objects. This implies that the worth of every individual regardless of ability, colour, race etc. must be appreciated (CPA, 1991). Proponents of F/C strongly emphasize the positive consequences of F/C, some of which are related to the requirements of this first principle. Biklen (1990), for example, has suggested that F/C may change our perceptions regarding the abilities of people with autism. That is, through F/C we may discover that autistic people are able to understand language, but that they need avenues other than direct speech and gesture in order to communicate. Furthermore, Calculator (1992) has suggested that use of F/C may contribute to new positive self-fulfilling prophecies. That is, if we hold low expectations of individuals, and

if we undermine the individual's attempts to communicate, the individual may become passive. If, however, individuals are encouraged to use their communication skills, they may be able to demonstrate competencies that had previously been "dormant" (Calculator, 1992). However, as Mirenda and Iacono (1990) emphasize, "merely believing that communication occurs and can be reciprocal will never be sufficient to make it so" (p. 3). Moreover, as clients requiring facilitation are dependent upon the close proximity of a facilitator, one might ask whether the creation of such dependency is beneficial to the client. Indeed, results of a recent multi-method validation study (Perry et al., 1994) indicate that some clients who use F/C develop an "abdication pattern" of response whereby they perform at a higher level independently than when being facilitated. Furthermore, if a client's communications are being influenced unwittingly or otherwise, the client in effect is being used as a puppet, an act which many would see as violating the individual's respect and dignity.

Despite the lack of empirical evidence supporting the validity of F/C techniques, and despite the intrusive nature of this technique, F/C is being widely recommended without due consideration being given to issues such as the individual's understanding of the alphabet or other concepts such as pictures before introducing a communication system. Indeed, the heavy emphasis by proponents upon competence and the respect and dignity issue frequently leads to confusion. When professionals recommend preliminary assessment of an individual's abilities and potential in order to determine the most appropriate augmentative communication system, proponents of F/C frequently argue that the professional is doubting the individual's competence and limiting their chances for integration and acceptance. It is important that these two issues be kept separate and not interfere with a careful analysis of the risks and benefits of this approach for individual clients.

a) The Issue of Informed Consent The ethical principle of Respect for the Dignity of Persons includes informed consent, which requires that individuals understand the procedures that will be undertaken. There are several issues to consider in this respect.

Although proponents of F/C emphasize that the use of this technique can have positive effects on the student's self-esteem and may enable the student to function more effectively in the classroom and in the community, there are several situations in which it is deemed inappropriate to use F/C. Given the lack of data supporting the validity of F/C, its use is inappropriate when informed consent is needed in order to participate in a research project, psychological assessment, or to receive medical treatment or counselling/therapy. Autism is a developmental disorder characterised by limited non-verbal as well as verbal abilities. Indeed, many autistic children function intellectually within the mentally retarded range (Lord & Schopler, 1988). If these two latter points are the case, then the individual's ability to comprehend the proposed procedures may be impaired, and it may not be possible to ascertain reliably that the procedures have been understood.

Informed consent also requires that the individual's decision to participate is independent and is not due to the coercion or influence of another person. As long as there is any doubt as to the validity or independence of messages communicated with facilitation, there is great risk of conducting research or applying particular treatments with individuals who use this mode of communication without truly having informed consent.

The CPA Code of Ethics makes it quite clear that when individuals are not capable of giving informed consent due to disabilities or because the individual is a young child, consent to participate must be undertaken by parents or legal guardians. One could argue that without validation of the independence of communications, consent is being

given by the facilitator rather than by the client. However, the question may be raised whether the benefits of apparent involvement in such decisions outweigh the risks to the respect and dignity of the client. It is essential to be sensitive to indications that the individual is distressed or is unwilling to continue participation. In such cases, the individual's participation must be discontinued immediately. A greater problem is faced in more frequently observed situations where individuals using F/C do not resist such intervention, but where independence of communication has not been determined.

b) The Question of Confidentiality The CPA Code of Ethics makes it clear that all individuals must be treated equally despite the presence of a disability. This includes the right to privacy and the right to obtain treatment that will be kept between them and the therapist in the absence of a third party. The use of F/C may pose a problem in keeping such commitments. Although generally speaking, the use of counselling or psychotherapeutic techniques with non-verbal individuals with autism would be considered to be inappropriate, parents or proponents of F/C who assume that an individual is able to communicate independently may request that he or she be interviewed or receive counselling. In such situations, if the psychologist questions the validity or independence of the communication, the relationship with the client is likely to end. A less threatening approach which also resolves the ethical dilemma is to consider the potential breach of confidentiality which is inevitable in cases where an individual is dependent upon a facilitator to communicate. As long as there is any kind of physical contact between the client and the facilitator and unless particular situations are set up where the facilitator is either not able to see the keyboard/letterboard or stimulus materials or is unable to hear questions being asked, it is unclear who is doing the communicating and therefore, who is the recipient of counselling.

II RESPONSIBLE CARING

A second ethical principle that must be considered, according to the CPA Ethical Guidelines, is that of Responsible Caring, which highlights the obligation that psychologists have to evaluate potential risks and benefits of a treatment and to do no harm.

F/C has been seen as a breakthrough by many parents and educators of autistic individuals who have become frustrated over failed attempts to set effective programs for their children (Minnes, 1993). Such parents and educators are then more likely to become enthusiastic when an alternative treatment is introduced. However, a question that must be considered is whether such an alternative method works because we inadvertently make it work. While psychologists have a professional and ethical responsibility to listen to the needs and concerns of clients and their families and to provide support, care should be taken to avoid contributing to the false hope and expectations that the autistic individual is competent and able to communicate independently; these expectations in many cases may result in disappointment and a sense of failure. Moreover, whether parents' experiences with F/C have been positive or negative, psychologists also have a professional and ethical responsibility to inform clients and their families of the potential risks involved in the use of F/C. The considerable distress and conflict experienced by family members and paid caregivers as a result of increasing numbers of allegations of abuse communicated through F/C (Rimland, 1992) attest to the urgent need for action in such matters.

a) Requests for Intelligence Testing As many proponents of F/C assume competence of individuals using F/C, requests for psychological assessments of individuals with autism using F/C are growing. Clearly, the potential risks and benefits of using intelligence and other tests in such instances must be carefully considered. In general, standardized administration procedures are required by

most psychological tests. Moreover, the individual being tested is expected to have similar characteristics to the test standardization group, and is expected to understand what is being asked of him or her. Violation of any of these criteria can severely limit the interpretation of test results.

With individuals who are using F/C, it is impossible to determine with absolute certainty whether or not the individual truly understands what is expected of him or her, since the communication is not independent and may be influenced by the facilitator (Rimland, 1992; Hudson et al., 1993; Wheeler et al., 1993). Here again, the validity of the test may be compromised. If, for example, the facilitator is inadvertently influencing the individual's responses on an intelligence test, it is possible that the individual's IQ score will be elevated. This may lead to expectations which surpass the individual's capabilities. In such a situation, the individual's performance will not meet expectations and feelings of frustration may, in turn, lead to disruptive behaviour, withdrawal, depression, and lowered self-esteem.

One alternative to using standardized intelligence tests such as the WISC III and the Stanford Binet would be to use tests such as the Raven's Progressive Matrices and the Leiter International Performance Scale which do not require verbal responses and therefore remove the need for facilitation.

b) Risk of Inadvertent Misuse and Misinterpretation Given the psychologist's obligation to evaluate potential risks and benefits of a treatment in order to prevent or protect from harm, psychologists can find themselves in a difficult position when working with clients using F/C. There have been several reported cases in which the use of F/C caused disabled individuals and their families considerable distress. These were cases in which disabled individuals alleged through F/C that they were being molested by a family member or caregiver (Rimland, 1992). However, in a number of cases (e.g., Hudson et al., 1993) these allegations have not been

confirmed and have been considered to be inadvertently influenced by the facilitator. Similar results regarding the lack of independence of communication have been reported by Wheeler et al. (1993).

Not only are psychologists responsible for protecting disabled children from alleged abuse, they also are responsible for protecting both the child and his or her family from potential abuse by trusted facilitators who unwittingly may be influencing the child's communication (Minnes, 1993). If allegations of sexual abuse are made, the removal of the child from the family can have potentially devastating effects for both the child and the family (Rimland, 1992). Given the uncertainty regarding the independence of messages communicated through F/C, it is the psychologist's obligation to attempt to determine the validity of such messages in order to protect, not only the disabled child, but his or her family as well.

III CONCLUSIONS AND RECOMMENDATIONS

The use of F/C techniques increased dramatically in the early 1990's and has continued despite considerable debate regarding the technique's validity and usefulness (Biklen, 1990; Calculator, 1992; Cummins & Prior, 1992; Minnes, 1992; Prior & Cummins, 1992). A question that might be asked, then, is whether, as professionals, in the absence of solid empirical evidence to support its use, we should have anything to do with clients who use F/C and their families or caregivers.

It is important to recognize that F/C may have some positive as well as negative effects on autistic individuals, both of which deserve careful empirical analysis. For example, regardless of the independence of communication, the assumption of competence may well have a positive impact upon attitudes toward persons with autism, and contribute to renewed enthusiasm among caregivers and increased opportunities for client interaction and stimulation. However, it is also important not to lose sight of the fact that without careful assessment, it is difficult if not impossible to determine the benefits of F/C

with a particular individual. It also is important to remember that F/C is not the only communication system available, and individuals should have the opportunity to learn other methods of communication that may be more conventional. Given the possible beneficial effects of F/C, it may be appropriate to consider it as one of several educational tools, but certainly not the only one. However, as indicated in a recent policy statement approved by the American Academy of Child and Adolescent Psychiatry (1993)... "information obtained via FC should not be used to confirm or deny allegations of abuse or to make diagnostic or treatment decisions." Moreover, caution is advised in instances where one is being asked to engage in activities such as assessment and or counselling which require informed consent and/or confidentiality. Finally, while psychologists are encouraged to approach the subject of F/C with caution, they also are encouraged not to dismiss it outright. Regardless of the growing body of empirical data supporting the presence of facilitator influence, the use of F/C continues to spread around the world. Without well controlled research, we may never truly understand the many complex processes involved in the widespread acceptance of this mode of communication.

Submitted: August, 1993

Revised: March, 1994

Accepted: April, 1994

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Résumé

L'utilisation récente des méthodes de communication simplifiée, de plus en plus employées avec les personnes souffrant d'autisme, pose un certain nombre de problèmes d'ordre éthique aux psychologues. Il n'y a pas d'appui empirique pour

valider les messages communiqués par la simplification. Cet article soulignera certains problèmes d'éthique propres aux psychologues dont les clients utilisent les méthodes de communication simplifiée. Le Code de déontologie professionnelle des psychologues (1991) lui sert de guide.

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