Disability Studies Quarterly
Spring 2001, Volume 21 No. 2
www.cds.hawaii.edu

Evidence of Literacy in Individuals Labeled with Mental Retardation

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Abstract

Facilitated communication (FC) is a technique that involves provision of physical support to an individual who has few or no verbal communication skills in order to allow that person to point or type. There have been many papers published that have failed to validate FC. This study examines reading ability in a group of individuals considered to have mental retardation who also use FC. Nine individuals and their regular facilitators participated in a controlled study in which FC users were asked to respond to multiple-choice, vocabulary-based computer game items in both nonblind and blind conditions. Sessions were taped, analyzed, and scored. Although none of the participants had revealed literacy in previous assessments, four responded to game items at a greater-than-chance level.

Introduction

Facilitated communication (FC) is a method whereby individuals considered to have significant intellectual disabilities such as autism and mental retardation are assisted to type or point to letters. This method is purported to allow individuals who do not communicate well, either verbally or through unassisted alternative communication methods, to spell out their thoughts. A trained facilitator provides physical support, touching or holding the hand, wrist, arm, or shoulder of the individual while she or he types.

FC is controversial for two reasons. First, the contact between the facilitator and speaker is thought to provide opportunities for undue influence. Second, many people previously assessed as having minimal academic skills appear to display literacy when provided with facilitation. This study focuses on the latter examining the ability of FC users to respond to vocabulary computer game items in the blind condition.

Since its introduction in the United States by Biklen (1990), the authenticity of FC has been vigorously challenged. The litmus test for FC has been the ability of the FC user to type correct messages in a facilitator-blind condition; that is, a condition in which the facilitator has no access to the stimulus presented to the FC user whether it be written or spoken words, symbols, or pictures. In many blind studies researchers found that FC users uniformly fail to demonstrate authentic facilitated communication (Beck and

Piroveno, 1996; Bligh & Kupperman, 1993; Bomba, O'Donnell, Markowitz, and Holmes, 1996; Eberlin, McConnachie, Ibel, & Volpe, 1993; Klewe, 1993; Moore, Donovan, & Hudson, 1993; Moore, Donovan, Hudson, Dykstra, & Lawrence, 1993; Perry, Bryson & Bebko, 1998; Szempruch and Jacobson, 1993; Wheeler, Jacobson, Paglieri and Schwartz, 1993). The studies cited employed a variety of designs to create blind conditions: barriers, screens, earphones, blindfolds, and message passing. Response modes included: open-ended responses, fill-in the blanks, picture or object naming, and multiple choice. In some cases facilitators and FC users were experienced and in some they were not. Several of the experiments included a distractor condition in which facilitators and FC users were presented with different stimuli. None of the studies confirmed literacy in FC users.

There are several studies that do provide evidence that FC may be an authentic mode of communication for some individuals with severe disabilities. Observational studies provide numerous examples (Biklen, Kliewer & Saha, 1995; Biklen & Schubert, 1991; Biklen et al., 1992; Olney, 1995). In each of these studies, participants spelled out messages that the facilitator did not expect or that were previously unknown. In addition, a handful of controlled studies have provided some evidence of reading, spelling, and communication among FC users. Cardinal, Hanson, and Wakeman (1996) allowed participants to practice the task of typing words that were presented without the facilitator present. They found that some FC users were able to pass messages in this fashion and that performance improved with practice. Weiss, Wagner and Bauman (1996) asked an FC user to respond to questions based on interesting stories that were told without the facilitator present. The participant, a boy labeled with autism and mental retardation, was able to provide specific answers. Vasquez (1994) introduced a variety of tasks and games. The two participants in her study were able to provide some accurate responses in the blind condition. Ogletree, Hamtil, Solberg and Scoby-Schmelzle (1993) found that an FC user was able to spell out some of the play activities that he had engaged in without the knowledge of his facilitator. Sheehan and Matuozzi (1996) discovered that 10 percent of the information disclosed by FC users in their study had been previously unknown to facilitators.

The purpose of the study was to discover whether FC users demonstrate reading and comprehension in the facilitator-blind condition. It differs from several other controlled studies in four ways. First, it is naturalistic. That is, FC users are introduced to blind and nonblind trials during the course of playing a game. Second, FC users maintain control of when and how long they play. Third, participants have an opportunity to practice the tasks that they are asked to perform in the blind condition. Lastly, testing takes place naturalistically, within the context of games.

Method

Participants

Participants were sought in urban, suburban and rural communities in a three-county region of upstate New York. Nine FC user/facilitator dyads participated in the study over a nine-month period. Participants included one adolescent and eight adult individuals labeled with mental retardation and eight facilitators. Each participant was

carefully selected based on pre-set criteria. All nine individuals had (a) engaged in FC with at least two facilitators; (b) produced words and sentences using FC; (c) used FC at least 18 months prior to the start of the study; (d) indicated an interest in participating in an experimental study of FC; and (e) demonstrated no literacy on previous tests of communication. Participants ranged in age from 16 to 42 (M = 28.5, SD = 7.3). Following are brief profiles from the records of the nine participants. Pseudonyms are used.

Warren is a 32 year-old man who is diagnosed as having autism. Warren's intelligence test scores place him in the severely retarded range. Records indicated that although he could repeat phrases given to him, Warren could not verbally supply missing words or concepts during testing. Prior to 1990 Warren had been considered by both school and program staff to be largely non-communicative with little or no intelligible speech. A clinician's report dated February 1990 indicated that Warren did respond verbally, but that his vocalizations were monosyllabic and barely audible. More recent reports confirmed this finding. Warren's record contain no evidence of literacy.

Deb is 25 years old and has Down Syndrome. Tests of Deb's intelligence place her in the severe range of mental retardation. Before Deb exited high school she received an age-equivalent of 4-0. A current speech report indicated that Deb was able to verbally describe multiple attributes of items presented, tell about physical conditions, associate feelings with pictured contexts, and classify and categorize activities and objects. In 1994 Deb was able to identify 9/10 symbols and words. However, she did not demonstrate recognition of word meaning or comprehension of oral spelling during this testing.

Gary is 25 years old and diagnosed with autism and pervasive developmental disorder. Tests of Gary's intelligence place him in the mild to moderate range of mental retardation. He scored in the first percentile of every sub-test of the WAIS-R indicating uniformly poor performance. During a speech evaluation, Gary independently and accurately pointed to 7/12 pictures named by the examiner. Gary's expressive skills appeared to be more limited; he achieved a score of 4/12 when asked to label and define pictures. His records indicate that Gary reads, but without comprehension.

Andrew is a 42 year-old man with the label of profound mental retardation. In his records, psychologists and speech pathologists described Andrew's functioning as characteristic of the late sensorimotor-early preoperational level of development. A speech assessment identified the following pre-language skills: following one and two-step directions; sorting by color and shape; matching; and understanding of basic concepts such as object permanence. There was no evidence of literacy in Andrew’s record.

Bart is a 29 year old man labeled severely mentally retarded with autistic traits. During a psychological assessment, Bart was able to orally name 14/21 common objects. Yet his score on the Slosson IQ test was 21. Based on his responses to questions (e.g., who, what doing, and where), Bart's receptive language skills were assessed to be at the 2-year 5-month level with a ceiling score achieved at 5-5 years. Bart's records contain no evidence of prior reading ability.

Jerry is 21 years old. He had a range of developmental disabilities due to Fetal Hydantoin Syndrome. Tests of Jerry's intelligence place him in the moderate to severe range of mental retardation. Scores on the Peabody Picture Vocabulary Test (PPVT-L) were 2-9 years for expressive and 3-5 years for receptive communication. Jerry's record provided no indication of literacy.

Pat is 31 years old. She was diagnosed with mental retardation when she was 17 months old. Pat is nonverbal, uses a wheelchair, and requires assistance with all activities of daily living. Pat's performance on tests of cognitive functioning place her at the sensorimotor stage of development. A communication checklist indicated that Pat could visually fixate on an object, visually track, nod her head `no,' vocalize a handful of words, and inconsistently hand a poker chip to a therapist or staff person to indicate the need for a drink. Before being introduced to FC, Pat had successfully used a binary choice system. Her record provided no evidence of literacy.

Nick is 31 years old. At age four Nick was diagnosed with autism and mental retardation. Administration of the Slosson intelligence test indicated a performance age of 2 years 11 months. This score corresponds to an IQ of less than 20 placing him in the profound range of mental retardation. Nick speaks, when prompted, using one-word responses. His record contains no evidence of previous literacy.

Millie is 16 years old and had been labeled with mental retardation and autism. Early reports and social summaries indicated that Millie was nonverbal with few adaptive skills. An administration of the Vineland adaptive behavior scale rated her daily living skills to be equivalent to 1-8 years, her socialization skills to be below one year and her motor skills to be 2-5. Millie's record contained no evidence of literacy.

Facilitators

Facilitators were selected who were most familiar with participants and who regularly provided facilitation support for them. Each had a minimum of introductory training in FC comprised of (1) a two-day workshop by the Facilitated Communication Institute at Syracuse University or (2) individual instruction by FC trainers equivalent to the 2-day workshop. All facilitators were female and Caucasian. They ranged in age from 25 to 60 years.

Settings

Sessions took place in settings that were convenient for participants and facilitators including participants' homes or group homes, agency offices and community program sites. Settings were selected that allowed for user-facilitator proximity, control of external interference such as noise and distractions, and good lighting and climate control. In most cases, the settings remained consistent for each participant/facilitator dyad throughout the study.

Materials

Participants used a standard personal computer (n = 5), lap top computer (n = 3) or Canon Communicator (n = 1). Educational computer games were used that were adult-

oriented, contained graduated difficulty levels, and examined spelling and reading comprehension. Response modes included multiple choice, single letter or number, and full word formats. Although seven games were used by participants during the course of the study, results of performance on *Word Attack*, *Multiple Choice Quiz* (Davidson, 1990) are reported here for the following reasons.

First, all nine participants attempted *Word Attack.* Second, *Word Attack* involves one key stroke to select A, B, C, or D to match word to definition making it easier to use for participants with coordination problems. Third, *Word Attack* features eight levels and contains ten word lists per level. Items are presented in random order for each list. The almost limitless array of possible items allowed players to practice the actual task without memorizing or predicting correct responses during blind trials (Figure 1).

Figure 1

Computer Game Response Format

Word Attack Plus, Multiple Choice

Player Selects A, B, C or D for Each Item

rate of speed	loyal
A cluster	A devoted
B devilment	B easily controlled or handled
C tempo	C thick, crowded
D autobiography	D lazy

Experimental Design

This study was designed to examine FC users' responses to vocabulary-based computer games in blind and nonblind conditions. Each FC user/facilitator dyad engaged in 7 to 10 individual, hour-long sessions. The researcher met with dyads for a total of 83 individual hour-long sessions (M = 9.22, SD = 1.03). Of the 83 sessions, 62 (75%) were videotaped. Data were not collected during 12 sessions because participants opted not to play computer games. Participant 5, Bert chose not to be videotaped and was audiotaped instead. Procedures were identical to those used in videotaped sessions with one exception: in the case of audiotaped sessions, the researcher used a checklist to track blind and nonblind conditions.

At the beginning of each session participants were asked to select a game. Each session began with a warm-up period during which the researcher reviewed the sequence of actions and the demands of the selected game. Rather than alternating nonblind and blind trials (e. g., ABAB design), one or more blind trials were introduced during each session as part of game playing. A trial was defined as sequence of ten or more multiple choice items consecutively completed on one game. Before a blind trial was initiated, the participant's permission was asked. If the participant indicated, verbally or nonverbally,

that he or she did not want to attempt a blind trial or wished to stop once initiated, the blind trial was ended regardless of the number of items completed. Learning to respond to game items in the blind condition was presented to participants as part of the game rather than as a test.

In order to maintain a naturalistic approach to testing, no barriers, earphones or headphones were used. Instead, a facilitator-blind condition was created individually for each dyad. The blind condition was created by turning the computer monitor away so that the facilitator could not see the screen, but the participant and researcher could. In each case both the researcher and the facilitator verified the blind condition. Videotaped sessions were used to confirm the blind condition. Facilitators supported eight of nine participants at the right hand, wrist, elbow or shoulder. The left-handed participant was supported at the left wrist. The researcher sat at the nondominant side of each participant in order to allow full view of the computer screen, participant and facilitator while being outside the direct line of vision of the dyad.

Post-test

A post-test was given to participants who responded to *Word Attack* items at a greater than chance level. The post-test was comprised of 10 *Word Attack* items to be completed without FC. In order to preserve naturalistic conditions no pretest was given. Instead, current psychological and speech assessments from participants' records were used to verify tested reading and communication skills prior to the study.

The post-baseline method was used rather than a pre-baseline for two reasons. First, the post-test allowed the researcher to control for incidental or developmental learning that might have occurred during the study. Second, a pre-baseline may have unfairly influenced the participants and created an atmosphere of failure.

Inter-rater Reliability

Videotaped sessions were viewed twice and transcribed. An independent observer viewed and rated approximately 10% of responses from nonsystematically selected segments of videotaped sessions. The independent judge scored items on two dimensions: nonblind/blind, and correct/incorrect. Percentages were obtained by calculating the number of items rated identically by the independent judge and the researcher over the total number of items examined. There was 100% agreement between the researcher and the independent judge in determining nonblind and blind trials. Agreement was 98.5% on the correct/incorrect dimension (see Table 1).

Table 1

Inter-Rater Reliability

RATING OF BLIND AND OPEN TRIALS

	Researcher (# of items examined)			Independent Judge (# of items with identical ratings)		
	Open	Blind	Total	Open	Blind	Total
Warren	15	19	34	15	19	34
Deb	13	16	29	13	16	29
Gary	6	28	34	6	28	34
Andrew	10	3	13	10	3	13
Bart	(all sessions audio-taped)					
Jerry	12	7	19	12	7	19
Pat	11	0	11	11	0	11
Nick	13	20	33	13	20	33
Millie	27	3	30	27	3	30
TOTAL			203			203

Inter-rater reliability for open and blind conditions: 100%

RATING OF CORRECT AND INCORRECT RESPONSES

	Researcher (# of items examined)			Independent Judge (# of trials with identical ratings)		
	Open	Blind	Total	Open	Blind	Total
Warren	15	19	34	14	19	33
Deb	13	16	29	13	16	29
Gary	6	28	34	6	26	32
Andrew	10	3	13	10	3	13

Bart	(all sessions audio-taped)					
Jerry	12	7	19	12	7	19
Pat	11	0	11	11	0	11
Nick	13	20	33	13	20	33
Millie	27	3	30	27	3	30
TOTAL			203			200

Inter-rater reliability for correct and incorrect items: 98.5%

Possible Threats to Validity

Participants in this study were experienced FC users and facilitators. They were not randomly selected from the population of FC users. Additionally, the sample of nine participants is extremely small. Clearly the selection procedure and sample size prevent generalization to all FC users and facilitators. The test was not double-blind. During each trial the researcher could see both the participant and the facilitator. Because the researcher was not in direct view of participants and facilitators, inadvertent cueing is unlikely, but not impossible. Allowing participants to initiate and terminate blind trials could potentially influence results. However, providing choice and control to participants was central to the design of this study.

Results

Analysis

A one-sample chi square test was used to evaluate nonblind and blind trials in which 10 or more multiple-choice items were completed. This goodness-of-fit test statistically compares obtained responses with chance-level response rates. Only the first response was considered in scoring. A significance level was set at $p<.025$.

In the blind condition, 4 of 9 participants achieved scores on *Word Attack* at a greater than chance level (Table 2). These scores were achieved when, on their first attempt, participants selected the letter that correctly matched the word with its definition and completed a minimum of 10 consecutive items in the blind condition. Warren attempted two games of Word Attack in the blind condition earning a score of 41% correct on one of the games ($X^2=5.94$, df=1, $p<.025$). Deb attempted five games in the blind condition completing more than 10 consecutive items on two of those attempts. She achieved significant scores of 69% and 56% on the trials ($X^2=13.56$, df=1, $p<.001$ and $X^2=8.33$, df=1, $p<.010$ respectively). Gary attempted four games in the blind condition. He completed more than 10 items on two of the games attempted obtaining significant scores of 50% and 70% ($X^2=10.00$, df=1, $p<.010$ and $X^2=10.80$, df=1, $p<.001$ respectively). Andrew attempted one game of *Word Attack* in the blind condition. He obtained a significant score of 57% ($X^2=7.71$, df=1, $p<.010$). The other participants did not achieve statistically significant scores on *Word Attack*.

Table 2

Individual Outcomes in the Blind Condition

Participant	Session	Percent Correct	Chi-Square
Warren	3	a	
		b	
		18/44(0.41)	X^2=5.94**
Deb	3	a	
		9/13(0.69)	X^2=13.56****
	5	a	
		9/16(0.56)	X^2=8.33***
	8	a	
		b	
Gary	1	a	
	2	15/30(0.50)	X^2=10.00***
	3	a	
	4	b	
	6	b	
	7	7/10(0.70)	X^2=10.80****
Andrew	1	b	
	4	8/14(0.57)	X^2=7.71***
Bart	2	8/17(0.47)	X^2=4.41 ns
		8/17(0.47)	X^2=4.41 ns
	4	5/23(0.22)	X^2=0.13 ns
	7	7/20(0.35)	X^2=1.07 ns
	8	8/19(0.42)	X^2=2.97 ns
	9	4/17(0.24)	X^2=0.20 ns
Pat	9	a	

Jerry		a	
Nick	4	8/19(0.42)	X^2=2.97 ns
Millie	1	b	
		b	
		a	
	3	a	
	7	b	

a Fewer than 10 items

b Did not play in condition (open/blind)

** X^2 was significant, df =1, p < .025

*** X^2 was significant, df =1, p < .010

**** X^2 was significant, df =1, p < .001

ns Nonsignificant

Performance on Post-test

The four participants who appeared to be successful on this test were given a post-test in which they completed 10 items without physical support. A comparative analysis between blind-facilitated and unfacilitated scores revealed a difference between these scores that was not statistically significant, probably due to the small sample size: t = 2.96, df = 3 (Table 3).

Table 3

t-Test Comparing Facilitator-Blind Scores

with Unfacilitated Scores on *Word Attack, Multiple Choice*

	Facilitator-Blind Score (n trials)	Unfacilitated Score (n trials)
Warren	41% (18/44)	30% (3/10)
Deb	69% (9/13)	10% (1/10)
Gary	70% (7/10)	50% (5/10)

Andrew	57%	(8/14)	0%	(0/10)

t=0.06, df=3

Discussion

This study provides circumscribed evidence of literacy among some FC users. Although four individuals achieved statistically significant scores, the difference between scores on blind trials and the post-test is insufficient to make this claim unequivocally. However, two observations warrant further discussion. First, the participant who achieved a score of 50% correct on the post-test was Gary who had demonstrated the greatest level of literacy prior to the study. Deb, whose records also contained indications of word recognition, was not successful on the post-test. If Gary can match vocabulary words without FC, perhaps others have literacy skills that have not been detected through different methods of assessment. Second, although not reported here, several participants demonstrated literacy by reading aloud from the computer screen, following written directions, and identifying synonyms through pointing or speech (Olney, 1997; Olney, in press).

There are a number of possible reasons for the superior performance of these FC users over that of participants in the majority of controlled studies. The process of testing itself may influence performance. This study featured multiple opportunities to succeed, practice on the target task, and a simple response mode. It allowed FC users to control when to start and stop blind trials. The materials used may have increased motivation. Participants seemed to enjoy the games. The researcher approached blind trials in a casual and informal way, encouraging participants and praising all attempts, regardless of performance.

Participants in this study responded more accurately to computer game items in the nonblind condition than in the blind condition. This pattern of responses is consistent with other controlled studies of facilitated communication. In addition, none of the participants succeeded in the first session. This is also consistent with studies that provided only one opportunity for participants to pass or fail.

This study has four critical implications. First, the abilities of FC users and others with severe disabilities ought to be viewed as open-ended rather than fixed. Although tests and evaluations provide important information about the abilities of individuals, they may not show the whole picture. Researchers and professionals should not allow the limitations indicated by tested performance to prevent experimentation with literacy and other academic activities. They should not rush to conclusions about an individual's potential based on tested abilities alone. Second, as Ogletree et al. (1993) have suggested, FC should be evaluated independently for each person. Third, the process and context of testing have an impact on performance. Individuals who do not reveal their abilities to read and comprehend written language in clinical testing may do so in more informal activities and settings. Fourth, FC may be a useful tool in assessment of language skills. This study suggests that FC may provide the level of physical and emotional support needed for individuals with significant communication impairments to perform maximally.

Clearly, the dialogue about the usefulness and validity of FC is not finished. Research is needed that replicates tests of facilitation that appear to work for FC users. It would appear that it is premature to close the book on FC. We have yet to discover who may indeed benefit from facilitated communication.

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