"I Am Intelligent": The Social Construction of Mental Retardation

Douglas Biklen
Syracuse University

Judith Felson Duchan
State University of New York at Buffalo

DESCRIPTORS: autism, developmental disabilities, facilitated communication, mental retardation, methodology, research

Mental retardation, like marriage, is a cultural concept and one that is framed within a complex set of understandings. The meanings of mental retardation are created from a particular cultural backdrop and from various points of view within that cultural context. Our aim in this article is to provide convincing evidence to show that mental retardation does not exist as fact separate from interpretation, but that it is a concept constructed to account for selected events, behaviors, or phenomena. Our evidence that mental retardation is a conceptual construction is drawn from the research and professional literature that contains two opposing views of retardation: the normative view that considers normal children and adults as a basis for understanding those diagnosed retarded and the competence view that sees the behavior of those labeled retarded as sometimes different from but not inferior to those diagnosed as normal.

Accompanying the opposing views of mental retardation are differences of opinion about how best to conduct research with individuals classified as retarded. Two research approaches exist that are comparable to the two views of retardation. One is the approach that sees the research endeavor as being that of carrying out experiments to reveal the objective truths about various aspects of retardation. Another approach holds that retardation differs depending on one's point of view. The aim of this second view is to substantiate various interpretations of retardation to explain why those seen as retarded do what they do. Researchers who do experiments are trying to discover factors that influence or characterize behavior of those who are diagnosed retarded. Researchers who carry out interpretive research do so in the tradition of ethnography or symbolic interaction; they ask how various aspects of retardation are understood (i.e.,

what meaning is ascribed to it?) by different members of a particular culture.

The two views of retardation and the two approaches to science are based in two understandings of reality and truth. The first view is that the events in the world have a discoverable objective truth, free from the biases of those viewing those events. This is the view of a positivist. The second is that events differ with the experiences of those engaged in them and that truth is a highly complex, subjective matter based within an interpreter's life experience. Depending on the researcher's particular emphasis, this is the experiencing, or phenomenological, view of the truth.

We will discuss how these two views of retardation, two views of science, and two views of truth apply to facilitated communication. We will argue that it is no accident that there is such a heated conflict among holders of the various dichotomous views. The conflicts reflect foundational differences between the two camps—differences that go deeper than either side may have ever imagined. Finally, we will address directly the questions often asked about facilitation and how they reflect a particular framework, and we will provide alternative questions to illustrate the point that retardation and research are socially constructed.

The Normative View and the Competence View of Individuals Diagnosed as Mentally Retarded

Mental retardation is a diagnostic category used by professionals to account for poor performance on intelligence tests or to account for other behaviors that are judged to be deviant. It is grounded in a medical framework that classifies individuals into diagnostic categories based on their display of symptoms and in a psychological framework that presumes that behavior mirrors fixed abilities.

The prevailing official definition of mental retardation from the American Association of Mental Retardation (1992) refers to individuals having substantial limitations in present functioning, as indicated by:

1. Significantly subaverage intellectual functioning. . . This is defined as an IQ standard score of approximately 70 to 75 or below. . . .

2. existing concurrently . . . with limitations in adaptive skills . . . in two or more of the applicable areas, (including) communication, self-care, home living, social skills, community use, self direction, health and safety, functional academics, leisure, and work. . . (pp. 5–6)

The official meaning of mental retardation is usually interpreted as a constellation of behaviors or deviations from expected norms of behavior that are attributable to subaverage intellectual functioning (as indicated by an IQ score). To determine retardation in an individual, the professional diagnostician must find deficits in that person's behavior that are associated with the diagnostic category and that are different from those expected in normal behavior.

This search and discovery of departures from a norm thus becomes the aim of the professional to diagnose an individual as retarded. The focus is on the comparison with typical behavior, rather than on what the individual may be thinking about what is going on. It is a conceptual construction based on a normative view of difference.

An alternative to this normative view of mental retardation is a competence view, also a conceptual construction. David Goode, in an article about a 50-year-old man, Bobby, diagnosed as "severely mentally retarded," focused on what the individual could do rather than what he couldn't do when compared with others who are normal. Goode found that:

Apart from his difficulties in making himself understood . . . Bobby had followed the direction of the conversation and had produced semantically meaningful, if ill-formed utterances. We began to appreciate that cognitively, Bobby was far more complex than we had supposed (Goode, 1992, pp. 204–205).

Among those who subscribe to the competency view are people with disabilities themselves, as seen through autobiographical accounts. A prevailing theme in these accounts is that the label of retardation should not be applied to anyone. Robert Bogdan concluded from his interviews of those diagnosed retarded that they say they are not retarded "because they have never really thought of . . . [themselves] as bad" (Bogdan, 1980, p. 78).

The equating of retardation with being "bad" is part of what is meant by a conceptual and social construction. An individual's actions are treated as "bad behaviors" by some individuals with whom they interact. It is this "bad" rendering of their behavior that those with retardation feel the need to counter.

There is also an effort by those diagnosed retarded to disaffiliate with their diagnosis, because being labeled retarded results in their lack of access to living and occupational opportunities. Patrick Worth, Cana-

dian president of the Ontario, Canada, chapter of People First, levied a national campaign to change the name of the Canadian Association for Retarded Citizens to the Canadian Association for Community Living. Worth has elaborated on why he does not accept his diagnosis: "Nobody has the right to label someone 'retarded.' " He pointed out that the label acts as a kind of punishment, keeping people from getting jobs and prohibiting them from living where they wanted. "It is demoralizing to see someone as a label instead of [as] somebody. I am somebody. My name is Patrick Worth. I am not retarded. I don't think anyone is. I think labels are unnecessary" (Worth, 1988, p. 48).

The Competence View of Retardation Expressed by Facilitated Communicators

Facilitated communication has of late given a voice to many who have been diagnosed retarded, thereby offering confirming evidence for holders of the competence view of retardation. More importantly, facilitated communication offers a new avenue of communication for those assumed to be retarded. Facilitated communication provides those with severe communicative difficulties with physical, communicative, and emotional support as they try to convey their ideas using an augmentative communication system such as a letterboard, picture board, typewriter, computer or electronic typing device. (Biklen, 1990, 1993; Crossley, 1988, 1992). One of the common messages typed after learning to communicate with facilitation is a desire to disaffiliate with the label of retardation.

Lucy Harrison (age 17), a facilitated communicator who types with a facilitator's hand on her shoulder or just above her shoulder, has described her existence before her learning facilitated communication as one of severe separation from a "real world" that normal people inhabit:

I . . . HAD AN AGENDA OF HOW I WOULD BE COMFORTABLE IN THE WORLD LK OF NORMAL PEOPLE AND HOW TO GO TO IT. I WANTED INITIALLY TO STAY IN MY LIFE OF MY WORLD AND NOT BE A PART OF THE OTHER WORLD THAT YOU LIVE IN. BUT I SLOWLY BEGAN TO DO SOME INTERESTING THINGS THAT MADE ME NEED TO BECOME MORE AND MORE A MEMBER OF THE REAL WORLD. (Watts & Wurzburg, 1994)

For Lucy, being disconnected from the "normal world" had nothing to do with intelligence, it had to do with her inability to communicate. She describes her journey from her separated existence to this real world as a major effort carried out with her facilitator, Mrs. Walsh:

I FELT THAT ALOT OF THE STEP S THAT WE TOOK WERE INTELLECTUALLY RIGHT BUT EMOTION-

ALLY EXCUCIATINGLY DIFFICULT. I HAD TO FREE
MY SELF EVERY STEP OF THE WAY. AND LUCKILY
MRS. WALSH RECOGNIZED THE DIFFICULT NESS
OF EACH STEP SHE ENCOUCH ENCOURAGEMENT TO
HELP ME OVER EACH HURDLE WE MET. WE
PLANNED THE STEPS TO INDEPENDENCE TO-
GETHER AND SHE WAS THE STRENGTH I NEEDED
TO MAKE EACH JUMP. ALTHOUGH THE MANY
JUMPS WERE NOT GR GREAT TO OTHER PEOPLE
THE LEAPS WERE LIKE JUMPING OVER SKYSTAPERS
TO M ME. (Watts & Wurzburg, 1994)

Lucy's progress is described as a fight against a
physical difficulty and a matter of gaining confidence
and determination. Indeed, her description of working
toward independence sounds very much like a person
describing what it is like to go through rehabilitation
after a serious injury, wondering if rehabilitation is
possible, marshaling the emotional strength to pro-
ceed, battling self-doubt, making plans, needing allies,
and seeing as huge gains what to others must seem like
small steps.

Lucy frequently types about "intelligence," render-
ing it as a feeling of competence from someone "in-
side," and describing how relieved she is that facilita-
tion has allowed others to see that inside intelligence.

THIS HAS CHANGED MY WHOLE LIFE. I CAN NOW
TELL PEOPLE HOW INTELLIGENT I AM INSIDE.
I CAN TELL PEOPLE WHAT I LIKE AND DISLIKE. I
AM ME AND EVERYONE CAN LOVE ME NOW BE-
CAUSE I AM A GOOD AND VALUABLE PERSON
(Biklen, 1991)

Learning to type has been my rebirti as a normal
person . . . someone who does anything tieh want
with their life. people understand that i am an in-
telligent person every one wants to be treated
with respect (McClellan, 1991).

Larry Bissonnette, a 36-year-old person previously
thought of as retarded, also describes his condition as
one of being unable to communicate because of phys-
ical barriers (Watts & Wurzburg, 1994). He now is able
to type with someone's hand on his shoulder and de-
scribes practice as a crucial ingredient to his current
success:

EXPERIENCE IS NOT TO BE DENIED. ITS HARD BUT
TOTALLY PURATANICALLY NECESSARY . . . PAIN-
FUL BOTH BUT CATHARTIC.

Sharisa Kochmeister is a 15-year-old who now can
communicate as her facilitator holds an arm above
hers. When asked what has made the biggest differ-
ence in her life now that she can type with no direct
physical support, Sharisa responded: "OTHER PEOPLE
KNOWING I'M SMART AND SELF CONTROL AND ES-

TEEM." Sharisa explained that she had to overcome
others' "DISBELIEF IN MY INTELLECT AND INTEGRITY
[and] MY OWN DOUBTS ABOUT BEING READY TO GIVE
UP SUPPORT AND CONTACT." She advises others to:
"GO SLOWLY, IN SMALL INCREMENTS. THE KEYS ARE
PRACTICE, PATIENCE AND PERSEVERANCE." (Watts &
Wurzburg, 1994)

Lucy, Larry, and Sharisa do not consider them-
selves mentally retarded. For them, the classification
of mental retardation was something imposed on them,
a terrible misunderstanding, a wall between the people
they knew themselves to be and the world. It was
something that stood between them and the chance to
be seen as valuable. Their difficulty, from their point
of view, is that they have a physical disability that
prevents them from being able to behave or commu-
nicate in ways that can convey their inner compe-
tence, their inner intelligence.

Reconciling the Normative and Competence Views of Retardation

Approaches for reconciling the views of retardation
will depend on one's view. Efforts at reconciliation
when based within a normative framework may ask
whether or not a person is really retarded or really
authoring messages. The question presupposes a nor-
mative comparison. If the person is not retarded he or
she is normal; if he or she is really authoring his or her
own messages, he or she is operating in ways that
normal people operate.

If the issue of reconciliation is framed within a com-
petence view, questions are raised as to how and why
the same person can perform so differently on differ-
ent tasks. Acceptable answers presuppose that the
person is competent. Further, it is assumed that peo-
ple can experience different points of view. Appeals
are thus made to help other people change their minds
away from the normative orientation. Larry Bisson-
nette, when asked how to convince critics of facili-
tated communication, answered: "POTENTEIALLY
THEY ARE LETTINGH ROAD TO KNOWLEDGE ABPOUT
AIUTISM NOW BE BLOCKLKED BY WATERS OF DISBELI-
ETREF" (Watts & Wurzburg, 1994). Subsequently, he
explained, "RACIAL SPAT OVER ACCEPTANCE OF AU-
TISTICS SHALL ABATE. THE RIDE TO ACCEPTANCE OF
FC BRINGS PROMISE OF WORLD PEACE FOR AUTISTICS
. . . PEOPLE WILL CHANGE" (personal communication.)

Proposed reconciliations from either side reflect the
very differences that need to be reconciled. To show
how reconciliations are likely to reflect the position of
the reconciler, we now turn to the different views of
what type of information is needed for conflict resolu-
tion by those subscribing to different views.

Those adopting the norm-based view are likely to
argue that the norm-based tests used to measure retar-
dation are less subject to influence and are better in-
dicators of an individual's true abilities. If individuals

show some competencies, those achievements would be seen as minor achievements by someone who is generally "low functioning." So, the language of Bobby, the person Goode observed, would be seen as an aberration in a person who is otherwise deficient. Below are the two views of Bobby's communicative competence:

Normative view of Bobby:

> Speech or language therapy is not recommended as prognosis for improvement is poor . . . client can communicate basic needs but cannot express complex ideas and understands very little . . . difficult to communicate with. A quick test of intelligence yielded a mental age of approximately 2.8 years. Clinician concludes that Bobby is severely mentally retarded (Goode, p. 200).

Competence view of Bobby:

> Our experience with the videotape discovery of Bobby's communicative competence and his superior native knowledge naturally led us to a systematic search for a whole range of socially adaptive skills that we had ignored in our etic interpretation of him. These competencies were not obvious and involved taking off "clinical blinders." Our growing emic conception of Bobby meant that virtually every "pathological" behavior we and others had identified in Bobby was open for review (Goode, p. 206).

Oftentimes the holder of the normative view must reconcile findings of competence that do not fit with the concept of retardation. This happens when someone diagnosed severely retarded does something that shows competencies that challenge the definition of retardation. One option is to conclude that the individuals were incorrectly diagnosed and were not retarded, after all. For example, when Bogdan and Taylor (1976) published an autobiographic account of a person labeled retarded, some readers responded by insisting that someone with such complex thoughts must not be "really retarded" (Bogdan, personal communication).

A second option is to challenge the authenticity of the competence report. Autobiographers who were diagnosed severely retarded, such as McDonald (in Crossley & McDonald, 1980), Nolan (1987), and Scott (in Seagoe, 1964) have all had their authorship questioned. Similarly, a counter literature is developing in the area of facilitated communication that challenges the authorship of messages communicated by those thought to be retarded (Cummins & Prior, 1992; Rimland, 1993; Schopler, 1991; Shane, 1993a, 1993b).

A third option is to alter the view of retardation to allow for unexpected competencies. Terms such as

"idiot savants" and "splinter skills," "hypergraphia," and "hyperlexia" have arisen to name conditions in which a person is able to accomplish acts that exceed what would be expected from someone with mental retardation (for examples of works in which such arguments are used, see Rimland, 1994; Silberberg & Silberberg, 1967; Whitehouse & Harris, 1984). The names explain the unexpected competencies as being aberrations in what is otherwise a more accurate rendition of the individuals—their low-level functioning as a manifestation of their mental retardation.

Those working within a competence view are sometimes stressed to account for why someone they view as competent has such difficulty performing tasks designed to measure competence. Why, for example, are those who are successful with facilitated communication unable to speak? Why, under certain circumstances, are they unable to perform on seemingly simple tasks of validation designed to determine their ability to author their own messages? In this case, the discrepancy in abilities is cast as a departure from competence rather than a departure from a measured level of retardation.

Accounts of the discrepancy from within the competence view have been varied. Explanations for poor performance on validation studies of facilitated communication include test anxiety, lack of experience/practice with test taking, time-limited testing, and failed confidence (Biklen, 1993; Crossley, 1994). Some have named specific deficiencies such as word-finding difficulties and/or motor disorders (Biklen, 1990, 1993; Crossley, 1994; Crossley & Remington-Gurney, 1992; Hill & Leary, 1992). And still others have tried to create different renditions of what it means to communicate so as to account for the differences in performance by the same individuals (Duchan, 1993).

Positivist and Experiential Approaches to Research in Mental Retardation

Studies of those classified as retarded often are carried out within a philosophical tradition that sees retardation as existing in the individual and as an objective fact that is measurable through objective means. Researchers working within this tradition often assume a normative perspective in that they aim to discover differences between those carrying the diagnosis and their nonclassified (i.e., "normal") counterparts. The aim of this philosophical approach is to discover facts concerning retardation about which one can be sure, or even positive.

This positivist tradition casts relationships of events in the world as causal, in which changes in one area are associated with or caused by changes in another area. To isolate these cause and effect relationships, the researcher aims to isolate aspects of the context

that may bear a cause and effect relation to one another, the independent and dependent variables. The researcher then designs a context in which everything remains constant and manipulates the independent variable to see its effect on the dependent variable. Subjects must be selected carefully, and contexts controlled carefully to achieve unambiguous results and to enable replication of the experiment. Statistical comparisons are made between groups or conditions to determine the role played by the manipulated variables or to compare the performance of the different groups. Performing controlled experiments are what some researchers within the positivist tradition have called the "scientific method" (Jacobson, 1993).

The positivist approach to research, although favoring experiments, also allows for naturalistic studies in which researchers might identify an aspect of the disability and determine which variables control those problem behaviors. These studies have used quantitative measures, requiring numerical and statistical techniques, as well as qualitative approaches involving analyses of patterns of behaviors.

An alternative research tradition to the positivist one is the tradition that views reality as being different depending on one's point of view. This approach to research that we will refer to as the "experiencing view" sees reality as experienced phenomena. It is compatible with the competence view of retardation, because it focuses on how one's perspective may affect one's view of retardation and includes within its purview the perspective of those diagnosed retarded. Experience-based researchers see retardation as socially constructed and as varying depending on who is viewing it and the circumstances of the viewing.

Researchers working within the experiencing view (sometimes referred to as the phenomenological view) see events and objects as alterable, depending upon the context of interpretation. Their philosophical stance toward truth is that the world has multiple truths, each constructed from the conditions at hand. One can, thus, never be positive about a particular interpretation of an entity, even under similar conditions, because events differ depending on the experiential background of the viewer, the situational conditions, and the cultural context within which the interpretation is made. Researchers in this tradition are interested in exploring and understanding people's presuppositions and ways of framing questions and the effect these frames have on these interpretations. Further, they recognize the importance of locating themselves *within* the discourse, not *outside* of it.

Those studying the experiences of retardation try to avoid biasing their results with expectations resulting from preformed hypotheses. Borrowing from the methods of anthropologists who study different cultures (e.g., Geertz, 1973), researchers who aim to understand the experience of retardation may spend considerable time carrying out ethnographic interviews (e.g., Bogdan, 1980; Bogdan & Taylor, 1976). They often participate in the daily lives of their subjects, observing how individuals make sense of what ordinarily takes place (Goode, 1992). A rich resource of insight can be provided from interviews with those diagnosed retarded and observations of them, with the aim of finding out how they interpret what is going on about them.

A common theme of this experiencing approach to knowing is its focus on how phenomena change depending on one's perspective. The researcher who studies experiential phenomena is interested in how people frame their views, in the concepts or metaphors chosen to explain events, in the experiences people have and how they interpret them. From this stance or posture, everything is problematic, nothing is a given, especially that which is officially recognized or which to many people might seem obvious. The aim is not to arrive at a perceived, single truth, but rather to understand various interpretations of phenomena. This approach to research does not lend itself easily to quantitative methods, but rather to qualitative approaches that allow one to discover naturally occurring, unexpected regularities and make sense of the complexities in the data.

We have been arguing that the normative view tends to carry with it a positivist perspective that regards the world as being made up of objective truths that can be hidden from a biased researcher. This view brings with it a methodology that requires the researcher to control for the extraneous influences such as experimenter bias. Thus, care is taken to use objective measures and create controlled experiments. A competence view lends itself more to a philosophical perspective that sees truth as a matter of interpretation. The aim of the researcher, therefore, is to take bias as given and to examine how particular interpretations are socially constructed through different frameworks. Each approach to research is taken by its proponents as science, and each approach brings with it a feeling that the other approach is lacking in its basic understanding of the research enterprise.

Why the Controversy About Facilitated Communication?

One's notions about mental retardation, about science, and about truth are likely to influence one's opinions about what is going on in the area of facilitated communication. Thus, it is not surprising that the professional discourse on facilitated communication includes a disagreement between those who believe the objectivist reports of the scientists who carry out controlled experiments and those who believe the sci-

ence of interpretivist researchers who report on their own or other's experiences with and systematic observations of facilitated communication.

The researchers based in a normative, positivist framework conduct experiments in which contexts are controlled so that facilitators cannot easily influence the content of responses of the facilitated communicators (Wheeler, Jacobson, Paglieri, & Schwartz, 1993; Eberlin, McConnachie, Ibel, & Volpe, 1993; Szempruch & Jacobson, 1993).

Others who live within this normative-positivist framework take the results of the experiments as being impeccable because of the way in which influence was controlled (Cummins & Prior, 1992; Rimland, 1993). Although there are several reports of success using facilitated communication in controlled circumstances (Calculator & Singer, 1992; Intellectual Disability Review Panel, 1989; Vazquez, in press), there is a group of researchers grounded in positivism who argue that many individuals who appear to communicate successfully are being influenced by their facilitators and are not authoring their own messages (Eberlin & McConnachie, 1993; Jacobson, 1993; Shane, 1993a, 1993b). These researchers characterize the accumulation of controlled studies that produce predominantly negative results as evidence enough that the method is not substantiated or that it is viable for only a small percentage of those using it (see, for example, Rimland, 1993). In their view, the truth is better revealed in the context of greatest experimental control and better revealed by quantitative/statistical rather than by qualitative measures. The research endeavor that is embraced is the experimental study in which researchers carefully control for influence, and the conclusions are cast unambiguously—if they fail to perform in a particular controlled experiment, communicators are presumed unlikely to be able to author the messages produced in uncontrolled contexts.

Experimentalists could embrace a competence view and, in keeping with that view, regard experiments in which people fail to confirm communicative competence as potentially flawed. The competency-oriented experimentalist could be expected to announce that, as a matter of logic, it is impossible to establish that anyone is incapable of demonstrating competence, much as it is impossible to prove that anyone is ineducable or to prove any null hypothesis. Further, it should be possible to develop experimental designs that allow production of findings consistent with those reported in qualitative/experiencing research. In fact, preliminary findings in several studies do report such findings, for example, of unexpected literacy skills (see, for examples, Cardinal & Hanson, 1994; Olney, 1994; Sheehan & Matuozzi, 1994). These studies differ from experimental studies that have failed to find unexpected literacy in people using facilitation; the studies confirming unexpected literacy incorporate some

or all of the following conditions: extensive practice with test taking (i.e., the process, not content); extensive time for response; feedback to participants on how they are doing with the tests; multiple-choice format to remove word retrieval and/or short-term memory difficulty; and opportunities for participants to inform the research process with their ideas about the conditions under which they might succeed. In other words, the test conditions begin to approach conditions of everyday (e.g., school/recreational) communication.

Others subscribing to the competence view of those classified as retarded favor a scientific framework for studying facilitated communication that allows for and even celebrates multiple sources of data. The aim is to understand the facilitated exchanges as a highly complex activity in which different messages are negotiated in different ways, with varying degrees of contribution from each of the partners. The experiential perspective takes as given that individuals influence one another. Indeed, communication is, by its very nature, an effort by the partners to influence one another—to request responses, to elicit answers, to persuade to a point of view, to teach new content, to support one another's efforts. It is unwanted, manipulative, or oppressive influence that needs to be guarded against, not influence itself.

The competence view, studied within an experiential framework would lead the researcher to collect data across time and under different circumstances to understand what might be going on for the participants. Data sources may include the descriptive reports, autobiographical accounts, and qualitative studies portraying the details of the method's successes and limitations (Biklen, 1993; Crossley, 1992; Crossley & McDonald, 1980; Eastham, 1992; Nolan, 1987; Oppenheim, 1974; Schawlow & Schawlow, 1985). Results that fail to confirm the communication abilities are taken as one part of a highly complex picture of communication (Duchan, 1993).

Researchers in this experiential tradition are more accepting of the reports of those experiencing facilitated communication. For example, they use as a data source the descriptions of communicators about their communicative difficulties. Biklen has quoted a facilitated communicator as experiencing "seething apparent wrong behavior," (Biklen, 1993, p. 189) and another as being frustrated at not being able to speak despite the ability to think: "I WAS TRYING TO TALK BUT WAS ABLE TO MAKE ONLY ANGRY SOUNDS" (p. 188). These reports lead the experientially oriented researcher to the conclusion that those who convey frustrations about carrying out motor activities are expressing valid feelings possibly emanating from an underlying motor disability (Biklen, 1993; Crossley, 1988; Eastham, 1992; Haskew & Donnellan, 1993; Hill & Leary, 1993; Oppenheim, 1974).

Some Responses to Often Posed Questions About Facilitated Communication in Light of the Competence View of Retardation and the Experiencing Approach to Research

We are now ready to address commonly asked questions about facilitation.[1] We have tried to show how research approaches and perspectives on disability are likely to influence the kinds of questions researchers of facilitated communication pose as well as the way in which they arrive at them. We will argue that all questions in some way reflect the perspectives of researchers. Some often asked questions reflect a positivist perspective, implying that there are objective truths about facilitated communication that can be discovered through research studies. They assume the existence of culturally decontextualized meanings for terms such as authorship, cuing, influence, and competence. We regard such a stance as too restrictive, excluding what we might regard as better approaches for understanding the social meaning of facilitated communication, mental retardation, and other concepts.

The approach to understanding the issues around facilitated communication that we advocate takes a step back from the often posed questions and asks why these questions? What are the cultural-social contexts in which they arise? What meanings do they imply? From whose point of view are they asked? How would communicators who are successfully using facilitated communication interpret the questions? And finally, how do we, subscribers to a competence view of retardation and an experiencing approach to research, think about, understand, and respond to questions from outside our framework?

What are the most important research questions? And by what methods should we address them?[2] Recent research has included extended descriptions of the method and examinations of how facilitated communicators think about the method. From the competence and experiencing orientation, we can expect considerable attention to what communicators and facilitators have to say about or demonstrate through their actions with regard to the circumstances and strategies that allow for communication. Beyond that, we are interested in knowing what issues and questions concern people who use this means of communication as well as those with whom they interact, including teachers, family members, friends, and others.

One question that seems to dominate both the positivist and experiencing literature is the question of authorship. This is most often asked in the following form: Are the words those of the person with the communication disability or are they really the words of the facilitator (i.e., transmitted through the person with the disability)? Although there is considerable evidence that typical communication involves cooperation from participants and is often co-constructed, this question implies that in any given communication situation, one person is the sole author of a message.

If authorship is viewed as a cultural construction rather than as a fact, the methods best suited for studying authorship are those that include an analysis of what is meant by it. Within the experiencing tradition, researchers might ask: What do people mean by authorship; how does any communication occur; and what is the meaning of communication or authorship to the people engaged in it? At a more specific level, questions such as the following arise: In those situations where the communicator types what the facilitator sees, does the communicator know he or she is doing so? If it is conscious, how does the person speak of it—as cue seeking, as influence, as manipulation, or as something else? When a facilitator or anyone is not consciously aware of his or her role in constructing a message, how does this impact our understanding of authorship?

The cultural notion of authorship as something belonging to one person alone predominates the current discourse on facilitated communication, particularly the public presentation of facilitated communication. Those with disabilities are perhaps clearest about the implications of being defined as author or not. Changes occur in their lives based on others' recognition of their ability to author significant communications. As noted above, those changes have been characterized as a rebirth, and a freeing from silence. Conversely, denial of authorship has been experienced as a kind of killing of the self. Speaking of himself in the third person, the Welsh author Christopher Nolan, who communicates using a head pointer as someone steadies his chin, writes: "he felt the knife go in between his shoulderblades, he heard the tramp of the jackboots . . . He smelt burning flesh but his body was ice-cold" (p. 106).

From the experiencing point of view, the cultural notion of authorship has been addressed in a variety of ways. These include textual analysis in which researchers note the different expressive styles of particular communicators who share a single facilitator, unexpected phraseology and spelling, recurring themes of particular individuals, conveying of information by the communicator that was unknown to the facilitator but which could be verified, eventual progress to typing without physical support and other observable behavior that teachers and others, as well as the communication users find compelling (Biklen, 1993; Crossley, 1994; Steering Committee, 1993).

In certain cultural contexts, people using facilitated

---

[1] We will address the questions posed to us by the journal editors, restated in abbreviated form. For a complete listing of the questions, see the editorial introduction above.

[2] This refers to the first of the editors' questions.

communication may be required to "prove" their communicative competence under controlled, experimental conditions. Such conditions are seen as truth-bearing not only by researchers in the positivist tradition but also by some in the media, in courts, and in schools and agencies serving those with disabilities. To them, results from experiments are regarded as truer tests of authorship than other sources. Indeed, in some cases, successful performance under controlled experimental conditions is being used as the sole criterion for defining an individual's competence. Researchers in the experiencing tradition may be interested in how such a construction of authorship-by-experimentation emerges, the assumptions underlying it, and its meaning for different groups.

Related to the concept of authorship is the notion of independence: How many individuals using facilitated communication are independent? What variables contribute to this phenomenon? How much time was required for people to achieve independence?[3] Independence, like authorship, rests in the mind and cultural context of its definers.

It is in contexts in which authorship is in question that independence is raised and usually in relation to physical rather than emotional, contextual, or technological support. Judgments of physical independence depend on one's definitions. Does the concept of independent typing include those individuals who type with a facilitator's hand on their shoulder? What about those who type, but with a familiar facilitator nearby (see Eastham, 1992, p. 84; Watts & Wurzburg, 1994)? What about those who develop the ability to point independently at multiple-choice selections or to yes and no before achieving the ability to type open-ended communication without physical support? Longitudinal research investigating communicators' growth to independence is sorely needed to understand the process and its elements. Central to this will be communicators' views on what it means to become independent and how it occurs.

Independence as an issue for those being facilitated is likely to take on different meanings than for others. As we have seen above, it may be perceived as frightening and as physically difficult. It may even be thought of as forbidding. For example, a student in Australia laments the consequence of seeking society's conception of independence (cited in Biklen, 1993). She commented that accepting independence as a goal "was too dreadfully frightening and so I do not make a big effort to achieve this." Because she could accomplish more with assistance, she saw independence as having to settle for less: "independence required a lack of achievement." Without support she is

plagued by a "lack of control of my silly directly autistic behavior." A "light touch on my elbow tells me that I am totally safe and that success is a constant and real possibility" (Biklen, 1993, p. 77).[4]

Connected to positivist notions of independence are questions about variables and timelines for rendering progress. Such questions are not often in accord with the experiences of most who are engaged in communicating with facilitation. For them, practice toward physically independent typing involves subtle and complex interactions which do not readily lend themselves to descriptions involving isolated variables; nor is it possible to identify an unambiguous time when success or independence is achieved. People who have discussed their efforts at becoming independent and those who have achieved it mention considerations such as practice, attitude (i.e., making a decision that independence is possible and something toward which the person wants to strive), patience, confidence, encouragement from supportive facilitators, and guarantees from facilitators that difficulty in achieving independence will not be used as evidence that the person is unable to communicate with facilitation (see Crossley & Remington-Gurney, 1992, pp. 40–41; Watts & Wurzburg, 1994).

Among those who have achieved the ability to type sentence level communication without physical support are individuals who have no intelligible speech and those who have limited, typically echoed or repetitive speech or who can speak in one-, two-, or three-word utterances. Crossley and Remington-Gurney note that of 430 individuals with developmental disabilities who were engaged in facilitated communication training at the DEAL Communication Centre in Melbourne Australia, 30 had achieved independent typing by 1991. One of these individuals took 6 months to achieve it whereas another took 6 years (1992, p. 41).

The questions concerning independence are not unlike those asked about facilitated communication in general. Under what conditions does the method work? When does it not work? With whom does it work?[5] These questions, in turn, force us to consider possible theoretical explanations for why facilitation might work for a given person or group of people.[6] We have outlined some possible reasons for why facilitated communication may be working for individuals who have failed to develop useful oral communication.

---

[3] These questions correspond with question 4 in the editors' list.

[4] One of the authors has subsequently observed this individual typing sentence level conversational communication with no physical support.

[5] These questions correspond to the editors' questions 5 and 6.

[6] This question corresponds to the editors' question 9 about possible theoretical explanations for facilitated communication.

Like all that we have discussed above, acceptance, confirmation, or validation of the theories will reflect the theorizers' approach to disability and to research. An experiencing approach might, among other things, examine the comments of those with the disability to arrive at a sense of how they experience efforts at communication and the role of facilitation. One, but certainly not the only, issue found in the words of communicators concerns movement difficulties.

Throughout the literature on facilitation (e.g., Biklen, 1993; Crossley, 1994; Eastham, 1992; Oppenheim, 1974; Schawlow & Schawlow, 1985), we hear commentary on physical difficulties getting in the way of reliable speaking and pointing and other activities. Margaret Eastham (1992) concludes that her son's

> apraxia prevented him from writing and speaking, as he could not copy movements and initiate movements on command, for example: smiling, blowing his nose, and spitting after brushing his teeth. (p. 60)

"Even simple things are hard," one student user of facilitation explains, "like moving a game marker" in a board game (Watts & Wurzburg, 1994).

In the video *Every Step of the Way* (Watts & Wurzburg,1994), we can observe Larry Bissonnette, mentioned earlier, struggle to get his finger where he wants to point. He selects the letter "d," then uses the back space to delete it before hitting the letter "f" to form the word "of." Also, we observe Larry shaking his hand out, taking a rest from an obviously taxing task. In the same video, Lucy Harrison struggles with an automatic completion, typing "ENCOUGH ENCOURAGEMENT" instead of "encouraged me." Such problems can be observed in anyone's typing, but they appear common in the work of individuals using facilitation.

Such difficulties are also expressed by those who have the same developmental disabilities but do not use facilitated communication. For example, Grandin writes about the difficulty of getting the correct words out: "In my head I knew what I wanted to say but the words never matched my thoughts" (Grandin & Scariano, 1986, p. 85). She found she could not "listen to the music and clap my hands rhythmically at the same time" (p. 30). She notes that for autistic children—she grew up with autism—"handling two motor tasks at the same time is almost impossible" (p. 30). The problem is described as one of failing to succeed with purposeful (i.e., intentional or voluntary as opposed to automatic) action (see Barron & Barron, 1992; Grandin & Scariano, 1986; Williams, 1994). Sean Barron, a person who can now speak and write fluently, describes his difficulties as a child with autism in learning certain motor tasks:

> I had a lot of trouble fastening buttons through the holes and tying shoes. Many times I ripped the buttons off my shirts and broke my laces because I was so furious with the damn things when they refused to work (Barron & Barron, 1992 p. 200).

He describes the frustration of being able to do something right one day and then not being able to repeat it the next (p. 62).

In light of these described difficulties with motor tasks, including speech and reliable pointing, some researchers (Biklen, 1993; Crossley, 1994) have suggested related guidelines for considering facilitation. These do not require prior evidence of literacy skills; it is presumed that if the method is found to work with an individual, the presence or absence of literacy skills will become apparent. The main considerations are that a person be unable to speak or have highly limited speech, for example, composed of echoed communication or confined to one-, two- or three-word utterances *and* be unable to point reliably.

Given the consistency of insider commentaries and researcher observations of motor planning difficulties, researchers will undoubtedly want to probe more deeply into the nature of these struggles, for example with problems of initiation and perseveration, with impulsiveness and modulation of pace in action, with loss of proprioceptive awareness, with control of the automatic and of the compulsive and obsessive (see, for example, Martin, 1994, p. 239), with eye-hand coordination and, most importantly, into the strategies that have allowed some people to overcome these, at least to the extent that they have been able to learn to point and type independently (e.g., Eastham, 1992; Watts & Wurzburg, 1994). Given what has been learned from facilitated communication users, much is already known about the conditions under which people achieve success with the method, including possession of personal confidence, practice of the method, access to communication devices, availability of multiple facilitators, and opportunities to use communication to affect one's life.

Researchers likely will want to explore the similarities of findings derived from experiences with facilitation to the existing literature in developmental disabilities having to do with motor disturbances/dyspraxia (see, for example, Damasio & Maurer, 1978, pp. 385, 393; DeMyer, Hingtgen, & Jackson, (1981), pp. 409–410; Fulkerson & Freeman, 1980, p. 335; Jones & Prior, 1985, p. 43; Losche, 1990, p. 749; Miller, 1986). Undoubtedly, researchers also will want to explore the role of touch in relation to developmental dyspraxia and how it may enable focusing and confidence and permit the person to begin action (i.e., overcome difficulties with initiation). Although a connection between touch and praxis has been reported in the literature (see for example, Sacks, 1990, p. 63), much remains to be learned about how it feels and what it means to the person who finds him- or herself

frozen without it and able to become unstuck in phys-
ical movements with it.

Although the quotations of people using facilitated
communication indicate the problems that some indi-
viduals have with movement, the experiencing ap-
proach would lead one to look for a variety of theo-
retical explanations supported by the discourse of ex-
perience. Other considerations might concern how
people with particular disabilities encounter the world,
including how they perceive it. How do certain indi-
viduals experience seeing, smelling, tasting, and
touching, for example?

Given the access to new knowledge that is becoming
available through facilitation, it is hard to imagine how
the costs associated with its implementation would not
be seen as a reasonable trade off.[7] Then again, wheth-
er or not the benefits of facilitated communication out-
weigh its costs is yet another question, the answer to
which does not lie in an objective truth, but rather is
constructed by the one answering. A competence view
of disability would hold that the most important life
change for those misjudged as incompetent would be
to have others view them as capable. But this require-
ment has always been true, well before the recent dis-
covery of facilitated communication.

The problem of how to create priorities for teaching
has also long been with us. The greatest cost, in the
competence view, is to treat a competent individual as
incompetent and to work on "skills" that are beneath
his or her ability. There is also a cost to working on
skills that exceed a person's ability. What one would
hope for is that people on both sides of this argument
could discover ways of focusing on the abilities of
those previously regarded as incompetent and dis-
cover ways to help them express those abilities.

Those finding the method risky point to the dangers
of significant messages of unproven authorship. This
question has been raised in the context of facilitated
statements in which people have accused parents or
others of having abused them sexually (Palfreman,
1993). It appears, however, that the incidence of such
allegations and the patterns of evidence associated
with them are not unlike those for the population with-
out disabilities (Botash et al., in press) and that the
means of resolving them resemble methods generally
used in the criminal justice system (Biklen, 1993, pp.
131–134; Borthwick, Morton, Crossley, & Biklen,
1992).

Some researchers have even suggested that it might
be unethical for the disability field to foster use of
facilitation.[8] The primary ethical question raised by

proponents of the method is one of access to free
speech. Will those who communicate with facilitated
communication be guaranteed a communication sys-
tem (facilitated communication or other augmentative
approaches) and, if so, will people listen to them? Fur-
ther, if listened to, will they be treated with dignity and
sensitivity? Finally, if listened to sensitively, will so-
ciety act responsively by guaranteeing their right to
self-determination?

We often are asked why the debate over facilitation
frequently turns bitter or at least adversarial.[9] We
have argued that the controversy about facilitated
communication is not just about whether or nor par-
ticular individuals are authoring their own messages,
nor is it about whether the method is successful or not.
It is not about what percentage of people can be
proven competent, or about the percentage who have
achieved or will achieve independent typing. It is not
about whether or not "developmental dyspraxia" or
"movement disorders" can account for the successes
of those using facilitation. It may be about ethics, but
only to the extent that ethics are related to the more
fundamental issues at the heart of the debate.

Instead of all these things presumed to be at the
heart of the matter by the questions posed to us, we
feel that what the discourse on facilitated communica-
tion has been about has more to do with presupposi-
tions underlying such questions. The presuppositions
reflect differences in views about the nature of retar-
dation and of science. If we are right that the current
debate does reflect these larger and older questions,
the adversarial positions it has evoked could have
been predicted. Debate is always most contentious
when basic, widely accepted concepts are called into
question.

References

American Association on Mental Retardation. (1992). *Mental
retardation: Definition, classification, and systems of sup-
ports,* (9th ed.). Washington, DC: Author.
Barron, J., & Barron, S. (1992). *There's a boy in here.* New
York: Simon & Shuster.
Biklen, D. (1990). Communication unbound: Autism and
praxis. *Harvard Educational Review, 60,* 291–314.
Biklen, D. (1991). "I'm not autistic on the typewriter" [vid-
eotape]. Syracuse, NY: Facilitated Communication Insti-
tute, Syracuse University.
Biklen, D. (1993). *Communication unbound.* New York:
Teacher's College Press.
Bogdan, R. (1980). What does it mean when a person says,
"I'm Not Retarded"? *Education and Training of the Men-
tally Retarded, 15*(1), 74–79.
Bogdan, R., & Taylor, S. J. (1976). The judged, not the

---

[7] This brief discussion of costs relates to the editors' ques-
tion 7.

[8] This discussion corresponds to the editors' question 8 on
the ethics of using or not using facilitation.

[9] Here we attempt to respond to the editors' question 10:
"What could have been done to prevent the adversarial po-
sitions that seem to have crystallized around facilitated com-
munication?

judges: An insider's view of mental retardation. *American Psychologist, 31*(1), 47–52.

Borthwick, C., Morton, M., Crossley, R., & Biklen, D. (1992). Facilitated communication and disclosures of abuse. *Facilitated Communication Digest, 1*(1), 5–6.

Botash, A., Babuts, D., Mitchell, N., O'Hara, M., Manuel, J., & Lynch, L. (in press). Evaluations of children who have disclosed sexual abuse via facilitated communication. *Archives of Pediatric and Adolescent Medicine.*

Calculator, S., & Singer, K. (1992). Letter to the editor: Preliminary validation of facilitated communication. *Topics in Language Disorders, 13,* ix–xvi.

Cardinal, D. (1993, November). Validation and facilitated communication: A quantitative study. Paper presented at the annual meeting of The Association for Persons with Severe Handicaps (TASH), Chicago, IL.

Crossley, R. (1988). Unexpected communication attainments by persons diagnosed as autistic and intellectually impaired. Paper presented at International Society for Augmentative and Alternative Communication, Biennial Conference, Anaheim, CA.

Crossley, R. (1992). Getting the words out II: Case studies in facilitated communication training. *Topics in Language Disorders, 12*(4), 46–59.

Crossley, R. (1994). Facilitated communication training. New York: Teachers College Press.

Crossley, R., & McDonald, A. (1980). *Annie's coming out.* Melbourne: Penguin.

Crossley, R., & Remington-Gurney, J. (1992). Getting the words out: Facilitated communication training. *Topics in Language Disorders 12*(4), 29–45.

Cummins, R., & Prior, M. (1992). Autism and assisted communication: A replay to Biklen. *Harvard Educational Review, 62*(2), 228–241.

Damasio, A. R., & Maurer, R. G. (1978). A neurological model for childhood autism. In A. M. Donnellan (Ed.). *Classic readings in autism* (pp. 383–405). New York: Teachers College Press.

DeMyer, M. K., Hingtgen, J. N., & Jackson, R. K. (1981). Infantile autism reviewed: A decade of research. *Schizophrenia Bulletin, 7*(3), 388–451.

Duchan, J. (1993). Issues raised by facilitated communication for theorizing and research on autism. *Journal of Speech and Hearing Research, 36,* 1108–1119.

Eastham, M. (1992). *Silent words.* Ottawa: Oliver Pate.

Eberlin, M., & McConnachie, G. (1993). Facilitated communication: Employing research results to develop ethical practice guidelines. *The Forum, 19,* 9–12.

Eberlin, M., McConnachie, G., Ibel, S., & Volpe, L. (1993). Facilitated communication: A failure to replicate the phenomenon. *Journal of Autism and Developmental Disorders, 23,* 507–530.

Fulkerson, S. C., & Freeman, W. M. (1980). Perceptual-motor deficiency in autistic children. *Perceptual and Motor Skills, 50,* 331–336.

Geertz, C. (1973). *The interpretation of cultures.* New York: Basic Books.

Goode, D. (1992). Who is Bobby?: Ideology and method in the discovery of a Down syndrome person's competence. In P. M. Ferguson, D. L. Ferguson, & S. J. Taylor (Eds.), *Interpreting disability: A qualitative reader* (pp. 197–212). New York: Teachers College Press.

Grandin, T., & Scariano, M. M. (1986). Emergence labeled autistic. Novato, CA: Arena Press.

Haskew, P., & Donnellan, A. (1993). *Emotional maturity and well being: Psychological lessons of facilitated communication.* Madison, WI: DRI Press.

Hill, D., & Leary, M. (1993). *Movement disturbance: A clue to hidden competencies in autism and related disorders.* Madison, WI: DRI Press.

Intellectual Disability Review Panel. (1989). *Investigation into the reliability and validity of the assisted communication technique.* Melbourne: Department of Community Services, Victoria.

Jacobson, J. (1993). Facilitated communication: Practice to research. *The Forum, 19,* 16–18.

Jones, V., & Prior, M. (1985). Motor imitation abilities and neurological signs in autistic children. *Journal of Autism and Developmental Disorders, 15*(1), 37–45.

Losche, G. (1990). Sensorimotor and action development in autistic children from infancy to early childhood. *Journal of Child Psychology and Psychiatry, 31*(5), 749–761.

Martin, R. (1994). *Out of silence.* New York: Henry Holt and Company.

McClellan, A. (1991). Breaking the silence. (Television segment). Sydney, Australia: 60 Minutes Australia.

Miller, N. (1986). *Dyspraxia and its management.* Rockville, MD: Aspen.

Nolan, C. (1987). *Under the eye of the clock.* New York: St. Martins Press.

Olney, M. (1994, May). A controlled evaluation of facilitated communication: Preliminary report. A paper presented at the Facilitated Communication Conference, Syracuse University, Syracuse, NY.

Oppenheim, R. (1974). *Effective teaching methods for autistic children.* Springfield, IL: Charles C Thomas.

Palfreman, J. (1993, October). Prisoners of Silence. *Frontline* documentary. Boston: WGBH.

Rimland, B. (1993). *Autism Research Review International, 7,* 1–2, 7.

Rimland, B. (1994). *Autism Research Review International, 8*(1), 7.

Sacks, O. W. (1990). *Awakenings.* New York: Harper Collins.

Schawlow, A. T., & Schawlow, A. L. (1985). The endless search for help. In M. F. Brady & P. Gunther, (Eds.), *Integrating moderately and severely handicapped learners: Strategies that work* (pp. 5–15) Springfield, IL: Charles C Thomas.

Schopler, E. (1991). Informal evaluation of Crosley's [*sic*] facilitated communication. [Letters to the Editor] *Journal of Autism and Developmental Disorders, 21,* 561–563.

Seagoe, M. V. (1964). *Yesterday was Tuesday, all day and all night: The story of a unique education.* Boston: Little, Brown.

Shane, H. (1993a). FC: Facilitated or 'factitious' communication. *Communicating Together, 11,* 11–13.

Shane, H. (1993b). The dark side of facilitated communication. A letter to the editor. *Topics in Language Disorders, 13,* ix–xv.

Sheehan, C., & Matuozzi, R. (1994, May). An investigation of the factors influencing the validity of facilitated communication. Paper presented at the Facilitated Communication Conference, Syracuse University, Syracuse, NY.

Silberberg, N., & Silberberg, M. (1967). Hyperlexia: Specific word recognition skills in young children. *Exceptional Children, 34,* 41–42.

Steering Committee. (1993). *The Queensland report on facilitated communication.* Brisbane, Queensland, Australia: Division of Intellectual Disability Services.

Szempruch, J., & Jacobson, J. W. (1993). Evaluating facilitated communications of people with developmental disabilities. *Research in Developmental Disabilities 14,* 253–264.

Vazquez, C. (1994). Brief report: A multi-task controlled evaluation of facilitated communication. *Journal of Autism and Developmental Disabilities, 24*, 369–379.

Watts, G., & Wurzburg, G. (1994). Every step of the way. [Videotape]. Syracuse, NY: Facilitated Communication Institute, Syracuse University.

Wheeler, D. L., Jacobson, J. W., Paglieri, R. A., & Schwartz, A. A. (1993). An experimental assessment of facilitated communication. *Mental Retardation, 31*(1), 49–60.

Whitehouse, D., & Harris, J. C. (1984). Hyperlexia in infan-

tile autism. *Journal of Autism and Developmental Disorders, 14*, 281–289.

Williams, D. (1994). *Somebody somewhere*. New York: Times Books.

Worth, P. (1988). You've got a friend. In D. Gold & J. McGill (Eds.), *The pursuit of leisure*, (pp. 47–52). Downsview, Ontario: G. Allan Roeher Institute.