

The FC Controversy

What is it?

Why is there a controversy?

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What is the FC Controversy?

**The FC user and the facilitator
are both involved in the
communication process.**

**How do we know whose words
we are seeing?**

Why is there a Controversy?

- **The facilitator often has physical contact with the FC user**
 - Support at the hand, wrist, forearm or elbow
 - Touch at shoulder, head, leg or clothing
- **Facilitator influence can and does occur**
 - FC users have typed information known only to the facilitator
- **Many FC users have not produced validated responses in controlled message passing experiments**
- **FC users' typing has often been far better than expected based on their diagnoses**
 - Sophisticated thoughts produced
 - Correct spelling and grammar
 - Nobody taught them to read and spell

Why is there a Controversy?

- **A growing number of FC users can now type independently**
- **Many FC users *have* produced validated responses unknown to their facilitators in controlled message passing experiments**
- **Many more FC users have produced validated responses unknown to their facilitators in the natural, *intended* use of FC**
 - Schoolwork, social situations, active participation in their own lives
- **Many FC users produce the same highly idiosyncratic language, regardless of who is facilitating them**
- **Standard IQ tests were not designed for non-verbal autistic individuals**
 - In a study with 38 non-verbal subjects, scores on the Raven Progressive Matrices (the “industry standard” test for non-verbal people) averaged 30 (and in some cases more than 70) percentile points higher than their Wechsler scales of intelligence scores

FC challenges long-held beliefs about the cognitive abilities of non-verbal people with autism

What Does the Literature Have to Say?

Peer-Reviewed Publications (1992 – 2006)

- **13 studies with negative findings**
 - Total of 162 subjects, largest study with 23 subjects
 - Several mentioned instances of authenticated communication as well
- **12 studies with positive findings**
 - Total of 80 subjects, largest study with 43 subjects
 - Instances of lack of communication and facilitator influence commonly reported
- **Many different approaches taken in the studies**
 - Formal, controlled testing procedures: Message passing, Object naming
 - Most produced negative results, but the largest test (n = 43) produced positive results
 - Carefully designed empirical observation of FC in “natural” conditions
 - Authorship Analysis
 - Linguistic-based studies in Finland and Italy found FC users to be true authors
 - Eye Tracking Studies
 - By tracking where the FC user was looking *before* typing letters, Dr. Andy Grayson of the UK found extremely strong evidence for FC users as the true authors of their typing in four of eight subjects he studied.

Why are the findings so different?

- **Not all studies ask the same question**
 - Some ask whether facilitator influence has occurred
 - Others ask if authenticated FC user responses have occurred
- **Determining correctness of some responses is not always clear**
 - Word finding problems – “Truck” typed, when correct answer was “Tractor”
 - Handling misspellings, extra letters in otherwise correct answers
- **Assigning authorship to some responses is not always clear**
 - Who is typing when “meta-communication” – responses that refer to the testing situation itself -- occurs?
- **Familiarity with the test situation is a prerequisite for success**
 - In all instances of validated responses in controlled testing situations, extensive practice with the test procedure (**not** the actual test materials) was provided.
 - First trials of the most successful test produced no successful outcomes
- **Need to allow enough time (up to 20 minutes) for the FC user to produce a response**
- **Results vary for the same FC user under the same conditions**
 - Fatigue, hunger, physical and emotional states of FC user are factors

Are controlled experiments the final arbiters of FC?

In situations where the response of the test subject is independent of the testing method, controlled experiments, when feasible, are best.

- **But FC users (and facilitators) are influenced by the test conditions, especially by the need to validate under often artificial conditions.**
 - Dr. Michael Salomon Weiss, a confirmed experimental psychologist whose initial response to FC was “ ... this thing is a bloody hoax”, decided to address FC himself. After working intensively with two FC users his conclusions were “We entered this area of inquiry as hostile skeptics, looking to protect our clients from what we perceived as extremely dangerous misinformation. However, our findings of observational and experimentally controlled validity, the emergence of independent typing, and data implying validity of this technique have given us some guidelines with which to proceed” (in his further study of FC)
 - Dr. Andy Grayson refers to *slippage*, “the process by which inferences are subtly and unintentionally misrepresented as observations - interpretations are presented as findings.”
“Performance is subject to the influence of all sorts of factors. ... So when a participant does not pass a test of their communication this does not necessarily mean that they were *unable* to pass the test. ... ‘Did not’ might mean ‘unable to’ but researchers have to argue their case for this interpretation, rather than implying that it can be directly read from the observational data.”
 - Dr. Mayer Shevin and long-time FC user Eugene Marcus decided to replicate a controlled message passing test. The story of Marcus’ extreme difficulty in doing so is both very informative and moving.

What We Do Know

- **FC does not work for everyone**
 - Lack of Response or Nonsense Responses Often Occur
 - Happens every time in one-time-only testing
 - Even under the best conditions 30% did not demonstrate communication.
- **Facilitator Influence Occurs**
 - Training of facilitators in Best Practices attempts to minimize this
- **Valid Communication of Facts Unknown to the Facilitator Occurs**
 - In both controlled experiments with blind facilitator and naturalistic settings
- **There are conditions that improve the likelihood of valid communication**
 - Naturally controlled conditions
 - Familiar facilitators
 - Test in the form of multiple trials over an extended period
 - Extensive practice with the test procedure (not the test data)
 - Sufficient time to respond
- **The ultimate goal of FC is to produce an independent communicator**

What We Don't Know

- **How to recognize beforehand who will and who will not be able to benefit from FC**
 - Until we can characterize that group, who should be denied the opportunity to see if FC can be an effective tool, among others, for them?
- **Why FC users perform as they do on one-time-only controlled tests with distractors and blind facilitators**
 - It is unlikely that experimentalists can provide the answer. Only persons with autism can give us any real insight into how much effect participation in this type of “make or break” test has on the ability of FC users to perform up to their abilities. Reading accounts such as Eugene Marcus’ and books by people such as Donna Williams and Temple Grandin may help us appreciate the burden such tests place on the FC user.
- **Why independent typers still need to have a facilitator nearby in order to type**
- **How to effectively measure the cognitive ability of non-verbal people with autism**
 - A review of 215 articles on mental retardation in autism published between 1937 and 2003 found 74% of the claims came from nonempirical sources, 53% of which never traced back to empirical data. Most empirical evidence for the claims was published 25 to 45 years ago.

Suggested Reading

- **Nancy Lurie Marks Foundation** has nice list of peer-reviewed articles, both pro and con http://www.nlmfoundation.org/about_autism/facilitated_comm.htm
- Perhaps the most frequently referenced negative study -- 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.
- ***Contested Words, Contested Science***, D. Biklen & D. Cardinal. Teacher's College Press, 1997. Contains chapters by Dr. Michael S. Weiss and by Eugene Marcus and Dr. Mayer Shevin, as well as a complete look at the FC controversy
- Emerson, A., Grayson, A. & Griffiths, A. ***Can't or won't?: Evidence relating to authorship in facilitated communication***. International Journal of Language and Communication Disorders, 36 (2001). (Supplement to) pp. 98–103.
- Any book by Donna Williams, (e.g., ***Nobody Nowhere, Somebody Somewhere, Like Color to the Blind***), probably the best insight into the minds of people with autism anywhere
- Any book by Temple Grandin (e.g., ***Emergence – Labeled Autistic, Thinking in Pictures***)
- Articles about mental retardation and non-verbal people with autism
 - Dawson, M., Soulieres, I., Gernsbacher, M. & Mottron L. ***The level and nature of autistic intelligence***. Psychological science: a journal of the American Psychological Society/ APS 2007;18(8):657-6
 - Meredyth Goldberg Edelson, ***Are the Majority of Children With Autism Mentally Retarded? A Systematic Evaluation of the Data***, Focus on Autism & Other Developmental Disabilities; Summer 2006, Vol. 21 Issue 2, p66-83