

WHAT CONSTITUTES EVIDENCE?

Why the debate about facilitated communication is important for ISAAC

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Facilitated communication training (FCT) is an augmentative communication (AC¹) strategy sometimes used for teaching some individuals with severe expressive impairments to point and to use communication aids with their hands. In FCT a communication aid user who has difficulty pointing accurately is helped by a communication partner (facilitator) to overcome neuro-motor problems and develop functional movement patterns. The immediate aim in FCT is to allow the aid user to make choices and to communicate as fluently as possible. Practice using a communication aid such as a picture board, voice output communication aid (VOCA), or keyboard in a functional manner is encouraged, to increase the user's skills and self-confidence and reduce dependency. As the student's physical skills and confidence increase the amount of facilitation is reduced. The ultimate goal is for students to be able to use the communication aid(s) of their choice independently. A detailed description of the most common hand impairments and the specific remedial strategies used may be found in *Facilitated Communication Training* (Crossley, 1994).

FCT is a teaching strategy of particular relevance to those people with severe expressive impairments who walk, for whom alternative access strategies such as switching or eye-pointing are impractical but for whom the acquisition of fluent manual signing or handwriting skills has proved difficult. Many such people are diagnosed as intellectually impaired and/or autistic. During assessment they typically demonstrate significant motor planning and sequencing difficulties. Those who achieve functional communication aid use through FCT may also

¹ We have used Augmentative Communication (AC) to include both augmentative and alternative communication, both because the politics which dictated the choice of that clumsy name twenty years ago are no longer germane, and in order to reduce confusion between references to the discipline and to the journal *AAC*.

demonstrate previously unsuspected knowledge or learning abilities in the same way as individuals who start to communicate using other AC strategies (Biklen,1993).

In the 1960s facilitation was used in the U.S. to teach children with autism to use handwriting as an AC strategy (Oppenheim, 1974). In Denmark, facilitated handwriting was used as a communication strategy by students with autism at Sofia School in the early seventies (von Techner, 1994; Pilvang, 2002). Facilitated typing and communication aid use was occasionally reported in the seventies and early eighties (e.g. Crossley & McDonald, 1980). It attracted widespread notice, however, only after the publication in 1990 of an article called "Communication Unbound; autism and praxis" in the Harvard Educational Review (Biklen,1990).

A few years later it was reported (in, for example, Hudson et al, 1993) that some people typing with facilitation had failed to communicate novel information to their facilitators when asked to do so by test givers. Other studies reported that people using communication aids with facilitation did communicate novel information (for example, QDFSIAA, 1993). The discrepancy between the research findings fuelled a heated debate about the nature of facilitation and its worth as an intervention strategy. A detailed analysis of the issues can be found in *Contested Words, Contested Science* (Biklen & Cardinal, 1997). During the course of the debate some individuals who had started to type with facilitation moved on to type independently (Beukelman & Mirenda, 1998, p. 327).

The ISAAC research symposium on FCT held at Odense in August 2002 raised some important issues with implications for AC as a whole. The small group who met to discuss FCT split into two camps - those who saw test scores published in refereed journals as more significant than the personal experiences of aid users, and those who saw the experiences of aid users as more significant than journal articles. The first camp showed impressive graphs and passed around substantial bibliographies. The second camp showed impressive videotapes and passed around books published by people who had started typing or writing with facilitation. At the end of the session neither side had altered their opinions in the slightest, because neither was speaking the other's language.

The immediate issue of debate was whether FCT had any value as an intervention. The negative case was presented as a numbers game. The number of subjects in a collection of refereed journal articles which contained negative or positive findings about the ability of individuals to communicate with facilitation was totalled to generate the number of 'failures' and 'successes'. The methodologies of the articles with negative results were accepted without question; on the other hand, the methodology of each article reporting success was examined

critically, some reason² being found to knock off each in turn until only one was left, a case study of a young child (Nußbeck, 2002). At this point a photo identified as the child in question was projected with a large question mark suspended over his head. The presenter said that while it was just possible he was the only person in the world to have communicated with facilitation it was more probable, given the burden of the negative evidence, that the article about him was false³.

As one of those who believe that FCT programs, used by trained facilitators working under supervision with appropriate safeguards, have produced positive outcomes for many people, one of the authors (Rosemary Crossley) was invited to present at the symposium⁴. Partly for practical reasons, and partly because of our long-term concerns about the lack of epistemological rigour in AC, her presentation focused on videotapes of people who had participated in facilitated communication training programs, on books written by people who had at least begun to augment their communication by typing with facilitation, and on the research issues that these raised.

At this point the unexpected achievements of some of the people who started to access keyboards with facilitation are so undeniable that we suggest, as did Beukelman and Mirenda, that we cannot any longer ignore FCT or automatically dismiss the output of facilitated communicators. It would follow that we then also need to ask why the AC field has ignored the achievements of these individuals for so long.

The Odense symposium on FCT did not resolve any questions about FCT or generate any specific research recommendations. It did, however, highlight a central problem of AC — the lack of any established criteria for evaluating practice, outcomes or research. AC remains a disparate and unconnected series of pragmatic methods without the recognised and codified common body of knowledge, and the procedures for identifying such common knowledge, that characterise longer-established professions such as medicine.

As AC now has its own peer-reviewed journal, its own professors and its own undergraduate and post-graduate courses, and as there is a widespread call for Evidence-Based

² Nussbeck's accounts of the articles she referenced were often inaccurate and consequently her criticisms were often invalid e.g. she says "In the Cardinal et al. (1996) study the subjects learnt delayed letter copying. There was no communication." (Nussbeck, 2002) The 43 students who participated in the study were told and shown words which they had later to type to their facilitators, who did not know what they had been told/shown. The researchers wanted to find out if the students could communicate information of which their facilitators were unaware. Thirty-two students (74%) did so successfully. (Cardinal et al, 1996)

It should not be inferred that our decision not to address each of Nussbeck's criticisms in this paper represents any concession as to their merit; we have chosen to focus instead on the more general issues raised by the debate and their implications for the future development of AC. Readers interested in a detailed discussion of the published research on FCT are referred to *Contested Words, Contested Science* (Biklen and Cardinal, 1997).

³ Such identification and criticism of individual research subjects is unusual, to say the least, and should surely be discouraged.

⁴ At the last minute, to replace a presenter who had dropped out.

Practice (EBP), it is essential that basic evidentiary issues are considered. At the moment AC is at risk of taking on the epistemologies of other fields without examining how relevant they are to what we actually do.

The simplest epistemology is that associated with the physical sciences. Knowledge is what can be measured, and the processes whereby knowledge is authenticated as real knowledge depend on the possibility of invariance and replication. The invariance required obviously limits the model's applicability. Every molecule of water will behave in the same way in a given set of circumstances as any other molecule of water (and any given molecule will behave the same at one time as at another), but the same cannot be said of complex life forms, especially human beings. Correspondingly, different authentication strategies are required to cope with our variability and complexity.

This individual variability means that we cannot simply adopt unquestioningly the validation strategies of other disciplines, as some AC researchers recommend. In, for example, an 'overview of the state-of-the-art in the [AC] field's attempts to provide a research basis to its clinical practice' Iacono (2000) says that the medical field has set the gold-standard for examining interventions by using double-blind crossover studies, but does not examine the question of whether this model is transferable to AC. And if one does examine the question, one finds, unfortunately, that the nature of crossover studies is such that they cannot be used for educational or behavioural interventions such as AC, where even double-blind studies are problematic.

While you can arrange for three months 'blind' administration of a drug to half your study group and placebo to the other half and then swap the groups over, there is no such thing as the blind administration of an educational or therapy program. You cannot have half a cohort of children taught to recognise words and the other half taught to recognise Blissymbols without the participants being aware of what they are teaching or learning. And you cannot attempt to verify your data by swapping the groups over, because at crossover the two groups will no longer be comparable.

It is not possible to double-blind, or even single-blind, a Macaw. It is not possible to have a blind evaluation of AC use; if you compare the person's communication before and after AC intervention, an alert evaluator will probably notice that the person has a device in front of them that wasn't there before. Even setting up blind assessment of a splinter skill is difficult, and generally involves screening those involved from the meaning of the tasks being carried out — ironic, when one considers that person-to-person communication is the issue being researched.

While some researchers in AC are aware of these epistemological issues⁵, they have not to date been addressed directly. There is thus no standard against which research or practice can be judged, apart from a crude assumption that articles published in peer-reviewed or refereed journals are more reliable than anything which is not peer-reviewed - more reliable, that is, than books, videotapes, or observations of real people. This assumption is crude in part because it takes refereeing as a universal panacea, without differentiating between journals, editors or reviewers, much less the experience of the authors or the calibre of their research. More fundamentally, the assumption is inadequate because it is not based on any evaluation of any of the other available forms of evidence. While this is an issue throughout academia, it has greater import in practical disciplines such as AC which have no universally-accepted knowledge base.

The status awarded to peer review relies on assumptions about the knowledge and impartiality of the editors and reviewers involved, and about their underlying epistemology. However, articles on AC face particular difficulties. An article on physics sent to any scientific journal will be reviewed by physicists, if only because they are the only people able to understand it, and it will involve calculations based on accepted formulae and measurements. Hundreds of scientific journals specialise in or include articles in physics, there are many appropriately-qualified reviewers, and researchers thus have a number of publication options.

AAC is the only refereed journal specialising in AC. While an article on AC submitted to *AAC* will be reviewed by appropriately-qualified AC researchers or practitioners and will have to meet basic criteria on terminology and practice before being published, far more articles on AC are written than can be accommodated in the pages of *AAC*. Many articles on AC are consequently published in profession-based journals (*American Psychologist*, for example), and diagnosis-based journals (the *Journal of Autism and Developmental Disabilities* – *JADD* — for example), whose editors and reviewers have quite probably no background in AC at all⁶.

Ill-informed peer review can result in the publication of egregious errors, such as the following:

“general delays or deficits in language function are closely related to general delays or deficits in intellectual development ... the everyday facility with which people with autism or mental retardation use a language (e.g., spoken, written, or pictorial) is an accurate depiction of their ability to do so ... there is no clinically significant phenomenon that inhibits the overt production of communication and "masks" normative [sic]

⁵ Some related points are covered in Bober, 2002.

⁶ The relative lack in AC of arcane terminology or specialist notation, while a strength from a practitioner's point of view, may contribute to a false notion that no special expertise is required to provide or assess AC interventions, or to review the resultant papers.

communication skills (i.e., actual production is representative of "internal" speech skill...). That there is a strong presumptive relationship, in general, between overt production and actual ability is a cornerstone of psychological assessment methodology, statistics, and psychometrics. (Jacobson, Mulick & Schwartz, 1995: 755).

This statement has just dismissed the use of AC with people with diagnoses of autism or mental retardation, and perhaps with anyone at all - after all, if 'there is no clinically significant phenomenon that inhibits the overt production of communication', what are we all doing?

Even when an article on AC happens to be reviewed by people with relevant knowledge, there is still no agreement about the relevant knowledge base or about what constitutes a valid measurement. Many authors uncritically accept measurements such as I.Q. scores from other fields and talk about diagnoses such as intellectual impairment as though they were as real as such other descriptors as weight or age. Most workers in AC, however, would be aware of at least one person who before they were given a means of communication had been labelled as having significant intellectual impairments but who has nonetheless gone on to demonstrate unimpaired cognition once able to communicate — as did, for example, Lucy Blackman, Jamie Burke, Sharon Kochmeister, and Sue Rubin, whose histories are given below. The existence of significant numbers of such individuals raises important issues about the validity of the intellectual assessment of any individuals with major expressive limitations.

The 'strong presumptive relationship' to which Jacobson et al refer above — axiomatic, in the sense of being both fundamental and intrinsically unprovable — is one reason why the epistemology of psychology is not appropriate for AC. To the extent that it is open to rebuttal, it has frequently been falsified by successful AC interventions. That presumptive relationship recently came under direct attack in a (refereed) journal article whose first author, Sue Rubin, had no verbal⁷ communication before she started to type with facilitation in the early nineties. She asserts that

AT THE AGE OF THIRTEEN JUST BEFORE I WAS INTRODUCED TO ... FACILITATED COMMUNICATION, MY IQ WAS TESTED TO BE 24. ...

I WAS THOUGHT TO BE RETARDED (BUT) ALL THIS CHANGED ... ONCE I COULD TYPE WITHOUT SUPPORT.... MY VERY EXISTENCE CHALLENGED BELIEFS ABOUT MENTAL RETARDATION.

ABLE TO TYPE INDEPENDENTLY.... MY PRESENTATIONS (AT CONFERENCES) WERE ACTS OF ADVOCACY. ONCE SOMEONE HAD SEEN ME, THEY WERE NO LONGER ABLE TO ASSUME MENTAL RETARDATION WAS PRESENT IN PEOPLE WHO LOOKED LIKE ME. WHEN PEOPLE SEE ME THEY

⁷ As usage in this area is not always precise, it may be necessary to specify here that 'no verbal communication' is used here to mean 'without words', as distinct from 'no oral communication', which is used to mean 'without speech'.

ARE FORCED TO ADMIT THAT THEIR ASSUMPTIONS ABOUT MENTAL RETARDATION ARE WRONG.
(Rubin et al, 2001)

This continuing reliance in AC on the inapplicable and impractical validation strategies of other disciplines has meant that we have not felt the need to devise our own standards suited to our own practice. The consequent effect of the lack of any theoretical foundations for an evidence base in AC is well illustrated by the brief examination of FC included in Iacono (2000). Iacono states that "... quantitative studies with objective measures have not provided support for the validity of the strategy. In fact, the evidence points to facilitators influencing message content...". Iacono supports this contention by citing two Brief Reports published in *JADD* in 1993 (Smith & Belcher, 1993; Hudson, Melita, & Arnold, 1993) which describe a total of nine people using communication aids with facilitation. As it happens, Iacono overlooked a number of other studies, including the largest quantitative investigation yet performed (Cardinal, Hanson and Wakeham, 1996). This study looked into the ability of people spelling with facilitation to provide novel information to their facilitators and involved 31 facilitators and 43 secondary students with severe communication impairment (SCI) associated with diagnoses of autism or mental retardation. Thirty-two of the students (74%) typed requested words to their 'blind' facilitators. However, the primary concern with the Iacono paper is not the omission of this research, but the lack of any established or accepted protocols for the evaluation of research into AC.

In, for example, Hudson et al, 1993 — one of the reports referenced by Iacono — the authors were psychologists who had devised a test protocol in which the subject (a woman without intelligible speech who had been diagnosed as intellectually impaired) and an untrained 'facilitator' were both fitted with headphones and asked different questions or subjected to white noise. The headphones precluded any oral communication from the facilitator to the subject, even to check whether she had heard and understood the question she had been asked (which was on audiotape and could not be repeated). In addition, the facilitator could not provide feedback, seek clarification, or provide encouragement. If this report had been sent to *AAC* or a speech pathology journal, one would hope that the reviewers⁸ would have asked some searching questions about the methodology, especially as to whether any baseline research had been undertaken to establish the effect of such an intrusive methodology on the abilities of a control group with uncontested communication; as it was, the paper was published in *JADD* and no such questions were asked.

The other report cited (Datlow-Smith & Belcher, 1993) described the unsuccessful implementation of what was described as a facilitated communication training programme with

⁸ If any - brief reports are not always peer reviewed.

eight adults diagnosed as autistic. As their description of the ‘facilitation’ makes clear, the ‘facilitators’ involved lacked the most basic understanding of the method, and omitted procedures they had specifically been told were necessary. Correspondingly, no training occurred — a straightforward replicability issue which should have been picked up at review, given that the authors themselves state that the ‘facilitators’ did not implement the method as outlined in facilitator training courses and materials. The outcome is as meaningful as the outcome of a Makaton signing programme would be if undertaken by staff who had learnt no Makaton signs. In another paper published in the same autism journal, Smith, Haas and Belcher (1994) report the negative results of tests administered to ten individuals diagnosed as autistic who had each had two (2) training sessions prior to testing with ‘facilitators’ whose own training consisted of attendance at one workshop about FC. Again, if these procedures had been used in a Makaton programme the negative results would have been unsurprising, (and would certainly not have been seen as worthy of publication in *AAC*).

Of course, finding some peer review procedures wanting does not establish what actually constitutes ‘good’ evidence in regard to AC interventions. Other models are available, however, and are illustrated by the following examples of non-refereed evidence and of evidence from different professional groups using different epistemologies.

Basic textbooks, if they want to run to more than a single chapter, are forced to set aside the full rigour of the experimental criteria. Beukelman and Mirenda, for example, are prepared to concede that truth may be found outside the pages of peer-reviewed journals. In the section on facilitated communication from the 1998 edition of their widely-used textbook, they describe an individual:

"Sharisa Kochmeister is a person with autism who at one time had a measured IQ score somewhere between 10 and 15 ... She does not speak. When she first began using facilitated communication (FC) several years ago to type on a keyboard, she required an FC facilitator to hold her hand or arm as she hunted for letters on a keyboard. No one thought she could read, write, or spell. She can now type independently (i.e., with no physical support) on a computer or type-writer.

Sharisa joins a small group of people around the world who began communicating through FC and are now able to type either independently or with minimal, hand-on-shoulder support. There can be no doubt that, for them, FC "worked," in that it opened the door to communication for the first time. ... We include FC here because of Sharisa ... and

others who now communicate fluently and independently, thanks to FC. For them, the controversy has ended."⁹ (Beukelman & Mirenda, 1998, 327)

Another form of evidence is that contained in a study of a series of abuse allegations published by a paediatrician and her colleagues at the Child Abuse Referral and Evaluation program at the State University of New York Health Center in Syracuse (Botash et al, 1994). Over a 3-year period 1096 children were referred to the program with suspected abuse, 13 of whom were said to have used facilitated communication to disclose abuse. There was corroborative or supportive physical or other evidence in 8 of the 13 cases - at least as much as would be expected in a similar number of cases not involving facilitation. The authors concluded that 'allegations of abuse that are initiated owing to an FC disclosure should be taken seriously'¹⁰.

Botash and her colleagues looked primarily at medical evidence. Dwyer, a lawyer, examined the way that related issues of evidence were handled by the legal system. (Dwyer, 1996) Law has its own epistemologies, which vary between jurisdictions. Standard cases are covered by the rules of evidence in each jurisdiction; cases at the margin, and cases that involve innovation, depend largely on what the particular judge regards as evidence. Dwyer records instances where courts accepted testimony obtained using facilitated communication, and occasions where such testimony was rejected, and concludes that "...the judicial approach of weighing the evidence on the scales of commonsense should not desert judges the minute they are faced with facilitated communication."

The strength of the legal principles of evidence is that the law recognises no authority other than its own, is not always impressed by expert witnesses, and is thus open to the proposition that (for example) an IQ assessment may be wrong or a condition misdiagnosed. The weakness of this approach is that the admissibility of evidence often rests on the opinion of a judge who may share many of the popular prejudices about disability, who may not have any relevant knowledge, but who nonetheless always has wide latitude to define the facts. The judge in one case was,

⁹ As it happens, in the early nineties before she learnt to type independently, Sharisa was involved in a major controversy when she alleged that she had been sexually abused by a carer. Iacono (2000) correctly says that 'FC achieved international notoriety' following such allegations; however, she then reinforces a common misapprehension by implying that all attempts 'to validate the communication of the individual with SCI have been unsuccessful, resulting in court hearings being terminated.' It is certainly true that Sharisa's allegations did not go to criminal trial, and her Family Court hearing was terminated; however, this was in fact because during the drawn-out legal proceedings she started to type independently. At this point the alleged perpetrator, who had previously claimed to be innocent, consented to a finding of sexual abuse and plea-bargained (Kochmeister, 1994). The restrictions on the publication of proceedings in the Family Court are such that the outcome would not have been known if Sharisa had not chosen to disclose it.

¹⁰ Over the period of three years, 13 children who disclosed sexual abuse through facilitated communication were seen at a tertiary care hospital outpatient child sexual abuse program. Previously determined developmental diagnoses included mental retardation, speech delay, and autism. Physical examinations found that four of the children had evidence of sexual abuse, two had physical findings consistent with sexual abuse, one also disclosed the allegation verbally [in speech], and one perpetrator confessed. Although the results neither support nor refute validation of facilitated communication, they suggest that each child's case should be evaluated without bias.

unsurprisingly, not convinced that an AC user could communicate by using a Canon Communicator (rather than a headpointer) strapped to her forehead (Dwyer, 1996). As appeals can only be based on matters of law, not matters of fact, factual errors in any legal judgement are unlikely to be corrected at any of the following levels of appeal, and such errors once made by any judge can become facts (just like errors in refereed journal articles) and may (like errors in refereed journal articles) be cited for generations.

In the ten years since the articles cited by Iacono were published there has been a plethora of first-hand accounts by people who first started to communicate verbally by using communication boards or keyboards with facilitation. The best known is *I Don't Want to be Inside Myself Any More* (1995), first published in German by Birger Sellin, a young man diagnosed as autistic and severely intellectually impaired. The most recent is *Lucy's Story - Autism and other Adventures* (1999) by Australian Lucy Blackman. Blackman, who had been diagnosed as intellectually impaired, now has an honours degree in English Literature. She and Sellin can now both type without facilitation. Where do AC users' autobiographical accounts - which have the advantage of being longitudinal and in depth, but the obvious disadvantage of dealing with one person only — fit in our evidence base? As it happened, no communication aid users attended the ISAAC research symposium on FCT held in Odense in August 2002, so their views on this issue were not heard.

Ironically, the voices of people who have used communication aids with facilitation are often heard elsewhere. Jamie Burke, a 16-year-old with a diagnosis of autism, gave a keynote speech to an audience of several thousand at the TASH conference in Boston in December 2002 — an achievement remarkable not simply because of Jamie's age and diagnosis but because he had been perceived as effectively non-verbal until the age of twelve (Broderick & Kasa-Hendrickson, 2001). Jamie had been typing with facilitation for some six years when he obtained a Lightwriter™ which spoke the words he typed. Shortly afterwards Jamie started to repeat the words the Lightwriter said. After some months he turned off the Lightwriter's speech and read back his typing without cuing. At the same time his spontaneous speech started to increase in functionality, fluency and sophistication, an improvement which is continuing (Broderick & Kasa-Hendrickson, 2001). In Boston Jamie read his speech and answered some questions by typing independently on a Lightwriter.

AC desperately needs longitudinal studies that look at real life outcomes for groups of AC users, not at such tangential issues as (say) whether non-disabled 7-year-olds find Compic symbols easier to recognise than written words. However, the significant resource requirements of such longitudinal studies unfortunately mean that they are likely to be funded not by academics but by government agencies whose evidentiary needs tend to result in the production of reports

rather than refereed journal articles. In such cases, furthermore, the funding agencies own the data, and the professionals involved may not even be at liberty to use it as a basis for their own journal articles.

One such example of a medium-length study with positive outcomes was the Facilitated Communication Project established by the Queensland Department of Family Services and Aboriginal and Islander Affairs. This involved 24 individuals assessed as intellectually impaired — 20 adults and 4 children — from a variety of residential settings. Considerable time was devoted to the training of the facilitators and to the baseline assessment of the trainees. A variety of strategies were used to assess the validity of communication produced with facilitation. Some of these did not involve typing. The output of those participants who did type or used spelling boards was collected over a number of structured conversational sessions with varying facilitators and subjected to style and content analyses. This showed that 13 (65%) of the 20 adults involved communicated information that was not previously known to their facilitators. For formal testing multiple-choice tasks were used. Overall the researchers found that ‘21 (87.5%) of the client sample of 24 had their communication validated using content and structural analysis’ within a year of starting to use facilitation (QDFSAIA, 1993, p 10). Of course, because this research was printed in a government report, not a refereed journal, it is omitted from most literature reviews.

The debate about FCT is important, not just for its impact on past, present and potential users and facilitators, but because it sheds light on some of the underlying (though often unexamined or unacknowledged) assumptions implicit in AC practice. Traditional AC often ties competence (first presumed competence, and then – inevitably – achieved competence) to access. There is a common (albeit generally unstated) assumption that language skills match access skills – that, for example, someone with the ability to communicate in sentences will be able to point accurately or operate a switch reliably – and, correspondingly, that failure to utilize the available independent access strategies successfully indicates that an individual has limited language skills.

If that were true it would make the provision of AC much simpler. We would never be haunted by our failures, by those people who, despite showing sophisticated comprehension, do not have the physical skills needed to access any of the currently-available AC strategies, or by those people whose output is generated so slowly and laboriously that it is not functional¹¹.

¹¹ After many months of practice with a single switch, Anne McDonald was able to generate ten words an hour. She wrote

“Yes, I want to be able to type independently, but if I can't get up to 400 words per hour it's not worthwhile setting up the technology. I have so little output for my efforts at the best of times that the thought of diminishing it further simply in order to be independent has no attractions for me.” (McDonald, 1988)

Where facilitation practitioners diverge from many AC practitioners is that they cut the knot between competence and access by reducing the access demands and increasing the output possibilities.

Sarah Blackstone has stated that EBP requires a research base, a quick way of accessing that research base, and clinicians with the skills to evaluate the evidence they find there. As she points out,

Even in medicine, with its thousands of researchers, multiple peer-reviewed journals, and double-blind trials this is a major issue. In 2001 Duke University's EBP Centre published an analysis of 1084 peer-reviewed journal articles on uterine fibroids. They found only 18 findings based on solid research. Given that an individual doctor could not conceivably read and analyse 1084 articles before deciding what to do for a particular patient, what does EBP actually mean for specific doctors and patients? (Blackstone, 2002)

Despite these problems, medicine has at least some advantages over AC — it has a large research base, and there is a consensus as to what constitutes reliable evidence. The Duke EBP researchers were able to call on accepted criteria by which they could judge the published research¹².

Before we in AC can commit ourselves to EBP we should decide whether we need a research base or an evidence base. In either case, we need to discuss and examine what constitutes evidence in AC.

If 98% of medical research, with its established protocols, is found wanting, what is the situation in augmentative communication? AC is a complex discipline, overlapping with education, linguistics, occupational therapy, psychology, speech pathology, medicine, and rehabilitation engineering. Its findings are of interest to journals that focus on specific diagnoses such as acquired brain damage, autism and 'mental retardation'. The editors of journals in these fields, and their reviewers, may have a very sketchy idea of AC, and no idea at all as to what constitutes an appropriate methodology for assessing AC interventions. The AC field has one refereed journal, *AAC*, which has never published an article about FCT — somewhat ironic, as there may be more publications on FCT than on any other single topic in AC.

¹² By finding that 98% of the articles studied did not meet these basic criteria, the Duke EBP researchers showed up one of the major concerns about basing practice on articles published in peer-reviewed journals — journals, editors and reviewers have variable standards. Their views on what constitutes a publishable article are based not just on the rigor and importance of the research, but on whether the article's conclusions match their own, and their knowledge of the authors (in many specialist fields and journals blind peer review is effectively a fiction).

In this situation, what constitutes EBP? Given the lack of any basic criteria for judging AC interventions which practitioners can apply to all articles on AC, do we just do what Nußbeck did and add up the number of ‘passes’ and ‘fails,’ disregarding all variables such as age, diagnosis, length of program, nature of program, equipment used and methodology? Do we genuinely believe that all the evidence needed for best practice in AC is (or ever will be) contained in refereed journals?

As we say above, the simplest epistemology is that associated with the physical sciences. This approach has had immense success in the physical sciences, and in all aspects of society that depend on the physical sciences. However, several practical elements underlie these processes of replication and measurement. One factor is that there are a large number of physical scientists, and there are a large number of physical scientists who are full-time academics. Another factor is that the work of these people has in a large number of cases considerable economic consequences, and these extend in steps away from the original discovery; if there is a flaw in the theories of quantum electronics, for example, your smoke detector won’t work. Because there is money involved, and because people’s ideas need to be passed around and tested, science has evolved a vigorous and meaningful publication culture. Any important idea will get into print sooner or later — indeed, anything really important will get into *Nature* or *Science*. None of these things are true of AC, or AAC.

Psychology has for over a hundred years aspired to be a science, and a ‘hard’ science at that. This has involved it in a commitment to replicability — the ability for an effect to be reproduced by other experimenters, at other times, with other subjects. Replication in physics involves the same substances being worked on in the same circumstances at different times by different people. In attempting to imitate this approach the discipline of psychology has privileged

- laboratory work, where the circumstances can be held constant to assist in replication;
- classification, as in DSM-IV, so that subjects can be sorted into groups that are [accepted as] for all relevant purposes identical, to assist in replication;
- the double blind trial.

All these processes have severe problems when applied to therapy. Laboratory work is, by definition, extracted from the context of everyday life, and may produce its own bias in behaviours; the classification system is crude; the double-blind trial is impossible to do with behavioural interventions (you can have two pills that look identical but are really different, but if two therapies look identical they are identical).

Furthermore, working with people with severe communication handicaps has its own range of evidential problems. An article based on a half-hour language comprehension test that was administered once a day for three weeks to five children might attain statistical significance but is not dealing with the kinds of children many clinicians see in situations where compliance is haphazard, medication variable, motivation seesaws, and arranging to have the children turn up at all is a full-time job in itself.

For this reason, a very large number of articles published in our official journal deal with experiments carried out by students on other students, who are much more amenable to the experimental mind-set. Even when an article is about people who do have a disability, however, it is very difficult indeed to determine whether or not the results are likely to be relevant to your clients, because the system of definitions of disability is almost terminally vague.

The DSM-IV definition of autism, for example, requires “A total of six (or more) items from (1), (2), and (3), with at least two from (1) and one from (2) and (3) ... and abnormal functioning in at least one of the following three areas...” Combinatorial mathematics established that there are thus 12,528 ways to be autistic, and that there is thus quite possibly very little overlap between the people diagnosed as autistic that the author is working with and the people you work with. Again, if our survey populations were measured in thousands rather than hundreds this factor might be less significant; but they are not.

Beyond that, too, come all the other possible sources of variability; the other disabilities that a person may combine with their autism, their background in home or institutional care, their cultural background, and their education, to name but a few. It is not, again, as if these things are simply sources of noise to be eliminated; we would expect to have to change our interventions in some way to accommodate them or take advantage of them. It is quite likely, too, that there will be some element of ‘intellectual disability’ included in the diagnosis of the people in any report. We believe this concept is fundamentally misconceived; it is in any case so wildly variable in its meaning between times and places as to be almost unuseable (Borthwick, 1994; Borthwick and Crossley, 1999).

We could add other hazards to the reporting of AC research. The work that is reported is such a minimal proportion of work done that it is hard to be sure that any success or failure that is reported is not the one random instance in a hundred that would be expected by chance. Norms for most of the qualities that we seek to measure have not been established for the populations we work with, and most of the norms that we use have been standardised on populations that specifically excluded our clients. The measurement of language mastery, in particular, is fraught with problems, which we have compounded rather than solved by using age equivalences.

All these problems spring from the general principle that people are not as standardisable as are electrons. Electrons do not have good days or bad days, or favourable or unfavourable environments. They do not change their minds, or lose their motivation. With people, it is impossible to specify all the variables in a situation, because these involve not only the physical environment (which can be standardised) but also the mind (which cannot). Anything anybody thinks about is, or can be, related to everything else they have ever thought about, or seen, or read, or heard; and that is a large number of variables.

We have already dealt with the problems of blinding and crossover in this area. We should add that even if a blind evaluation could be arranged, the fact that the person and the people with whom they communicate have to know the method leads us to the next issue, which is that communication is not an independent and severable variable, it is functional only in context, and the context is the social fabric of the life of the client. We are all aware of the Hawthorne effect, where any intervention has a positive effect simply because the subjects are pleased to have someone taking an interest. It is generally taken to be simply a confounder, a source of noise in the data that should ideally be factored out. In AC, however, the Hawthorne effect, or something very like it, is actually part of the therapy. We want the people around the client to perceive him or her differently, and thus interact with him or her differently, we would expect that introducing a method of communication to someone who did not have one would change people's perceptions, and we would expect that change to have positive effects on the client's motivation and on other people's receptiveness to their communication. The effects of raised expectations are not severable from the effect of the intervention itself; they are part of the intervention.

If, then, the double-blind randomised crossover trial is the summit of the scientific hierarchy of evidence, and if this summit of the scientific method is unavailable to our discipline, what does that say about us? Is AC doomed to be a scientifically second-rate backwater? Alternatively, what does our dilemma say about science, if science requires the impossible? Luckily, there is a way out of this dilemma. It is actually not science that demands this of us; it is its evil twin, scientism – “a narrow and often rigid definition of science” (Bannister, 1987). In practice, scientism is the belief that there is a simple set of ritual practices that when repeated mechanically confer the aura of science on a project.

Science does not consist of a particular set of laboratory procedures; it consists of using those procedures when they are appropriate and using other procedures when they are not, and applying thought to what makes them appropriate or inappropriate in any given situation. AC is not a laboratory science where you can hold a situation in suspension while you adjust one variable after another until there remains only one difference between your experimental subjects whose effect can then be measured accurately. An AC intervention requires us to work with an

enormous number of variables that are not constant, not susceptible to numerical measurement, and not subject to our control. The appropriate recording method for such situations is rich description, and the appropriate format is the case study or case series. If we are to look for a model, let us look to education rather than physics — and we mean education, not special education, which itself tends to lean towards behaviourism (Tawney & Gast, 1984). In AC our work involves understanding more than it involves measurement.

What, then, are the consequences of our having misunderstood the appropriate form of our science? The most immediate is that our evidence base has been severely stunted by a contempt for nearly all the kinds of evidence that we actually use in our practice. The views of successful aid users, the successes of our fellow therapists, the observations of parents and carers, are all written off with the dread term ‘anecdotal’, and there is a widespread view that anecdotal evidence is not simply inferior to laboratory studies but is not actually evidence at all.

This may perhaps be the reason why what might seem to an outsider the obvious remedy - looking at actual data - has to be ruled out. If you claim your experiment occurred in a certain manner and that certain things happened, you cannot support your contention by producing (say) videotape of an experiment that shows those occurrences or those happenings. That would be to go outside the frame. Only numerical data that can be — that has been — set down in the pages of a journal has any bearing on the argument.

In the debate on facilitated communication training, for example, the existence of actual people who started to use communication aids with facilitation and now do so independently is still regarded as totally irrelevant by many critics. Beukelman and Mirenda said “Sharisa ... and others ... now communicate fluently and independently, thanks to FC. For them, the controversy has ended.” (loc cit, 327), but they would appear to have been over-optimistic. Certainly, it might be thought that the actual physical presence of such students with newly-developed independent communication, and their testimony as to the nature of their previous difficulties, would have retrospectively established the existence of a phenomenon, 'clinically significant' or no, that had evidently until this time inhibited their overt production of communication and 'masked' their normative communication skills. It might be thought also that the existence of people displaying evidence of a hitherto apparently unrecognised communication-inhibiting phenomenon would at least establish that such a phenomenon was not impossible. This would be to misunderstand the nature of belief systems in this area.

One critic of FCT, for example, put forward as an important prop of his disbelief in the validity of FCT the argument that "Not one alleged competent user of the technique has come forward to prove the technique is genuine." (Shane, 1993a: 13) The next issue of the same

publication contained an article by Anne McDonald, a purported user, titled "I only have one life and I don't want to use it all proving I exist" and giving details of validation tests she had undertaken (McDonald, 1993: 21-22). Shane's response did not comment on the material McDonald had adduced as evidence for the validity of her communication, resting instead on a more basic exclusionary principle: "In light of my conclusions [as given above] in the paper FC: Facilitated or 'Factitious' Communication, it would be illogical to direct a response to Anne McDonald." (Shane, 1993b: 10) This would seem a particularly effective Catch-22; the method cannot be validated unless users come forward to give evidence, and evidence presented by users cannot be entertained because the method has not yet been validated.

It might be thought that these arguments do not apply to those people who communicate independently, and for them there is a different Catch-22; if they achieve independence then "Is not the final independence of [a person using FCT] evidence of the fact that she does not need FC and probably never needed it in the first place?" (Dockerell & Stirling, 1997)

Similarly, several of those who attended the ISAAC research seminar and saw for themselves videos of Sharisa and other independent typers nonetheless later published a petition against FCT (Biermann, Bober & Nußbeck, 2002). Reality is not considered knowledge.

Replication is an essential therapeutic tool, and we all want to copy and be copied, but when one is dealing with unstandardised and unstandardisable elements such as people, lack of replication cannot be a mode of disproof, and it is unscientific to import this error into our discourse. If I cannot get the results you claim, it is possible that you are mistaken, but it is also possible that the people I am working with are significantly different or that my approach varies in some respect not specified in your methodology because it was not perceived as central to your research. Perhaps, for example, you automatically speak first to the AC user and then to their carers, and I do the reverse. My failure to replicate your results is certainly not proof that you must be wrong, as it would be in, say, chemistry.

The full rigor of scientism's attitude to the reports of people with disabilities and their families is demonstrated by the reports of three inquiries — two into facilitated communication (American Speech-Language-Hearing Association, 1994; ADD/OSERS, 1996), one into autism (Medical Research Council, 2001) — that had in their terms of reference instructions that they were to consult with people with disabilities and their families and take account of their views. All three solicited and received submissions from the public. All three then announced in their reports that they had ignored all submissions except articles published in refereed journals. To pay any attention to what they had heard and seen would be unscientific.

The full rigor of scientism's attitude to case studies is demonstrated by the commentaries on an article by one of the present authors published in the *European Journal of Communication Disorders* (Crossley, 1997). The commentators objected to a particular case study of a successful intervention with a young woman on the grounds that there was another possibility — “Most crucially, was there anything else that could have contributed to Sarah's improvement happening in her life over this time?” (Dockerell & Stirling, 1997) Well, yes, other things were happening in her life, and there will never in this world be a case where this is not true of every person involved. While this is a *reductio ad absurdum* of the belief that all variables can be standardised — it is, as Chomsky said in another context, not so much an argument as an expression of lack of interest in the concept of explanation — it is none the less perfectly compatible with the ideology of scientism.

Having said this, what is the alternative? If we in AC have no general laws, and a lack of generalisable diagnoses, and limited resources for research, what knowledge can we hope to establish? There is one viewpoint that says that there is very little that can be done, and that this is just fine. Carmel Lum's “Scientific Thinking in Speech and Language Therapy” (Lum, 2002) is “a book written for students and practitioners who are interested in finding out what it means to know and how one can recognize valid knowledge” (Lum, p.xvii). She defines science as “the ‘precise, methodological laboratory practices associated with physics” (Lum, p.15). She believes that science relies on the demonstration of clear causal explanations; however, she acknowledges also that in therapy ‘it is quite difficult to isolate events that contribute to the causes of others’ (Lum, p. 63). In her vision of science, too, the hierarchy of evidence is topped by the Randomised Clinical Trial (RCT). However, as Lum herself says, ‘In many instances it is simply not possible to evaluate patients in terms of RCTs.’ (Lum, p. 53). She, along with many others, believes that ‘science’ after the model of particle physics is the only form of valid truth, and if a discipline is not ‘scientific’ in that restricted and laboratory-bound sense then it must be false.

At the end, Lum does accept the logic of her argument. If there is no truth but science, and if therapists cannot do science, then there is no truth to be gained from therapy.

... the speech and language therapy discipline ... acquires its theoretical perspective on a particular condition from one of the other domains [such as psychology, medicine, linguistics, sociology] and applies this knowledge to the treatment of a communication disorder. (Lum, p.2)

and thus

Progress in areas of speech and language therapy could be secondary to the developments in these other primary disciplines. (Lum, p.3)

This viewpoint is both misguided and destructive. It is, nonetheless, the logical consequence of the evidential requirements demanded by writers such as Iacono and Nußbeck.

Indeed, if the field of AC was able to do no more than establish that the field of communication is complex and individual that in itself would a step forward. This point may sound simply a statement of the bleeding obvious, but it is nonetheless in many ways inconsistent with the practices and concepts of other disciplines (as the quotation given above from Jacobson, Mulick & Schwartz demonstrates).

The field of AC was not created by following a scientific prescription, and it cannot be refuted by pointing out its divergences from scientific theory. The AC field exists, and it exists because there is a real need that we fill. AC therapists have demonstrated that communication can be improved across the spectrum of disablement. While this may again sound obvious to an AC audience, it was not always something that could just be assumed; psychology had claimed to prove objectively that the causal explanation for lack of language skills was low IQ, or low mental age (Jacobson, Mulick, and Schwartz, 1995)

Our discipline is actually based on a claim that we can do important things that not only are not possible in other areas of science but that are in fact inconsistent with certain of their claims of knowledge. All the work we do each day with clients serves to prove that unaided production is a very poor guide to actual ability, and that, therefore, the disciplines of psychological assessment, statistics, and psychometrics rest on a crumbling and unstable cornerstone. If AC is right, a cornerstone of psychological assessment is wrong.

The confusion in our AC epistemology stems from the fact that we have not based our knowledge on that insight. Our basic knowledge consists of the fact that language is easy to disrupt but very difficult to eradicate. Our techniques, useful as they are, are secondary to that core insight. The substance of our learning should be the words of those we have enabled to communicate, telling us in all the richness that we can access, the importance of communication, the experience of living in silence, and the stories of how they found help. Stories are evidence - stories that include as much of the interactions, the perceptions, and the emotions of the therapy experience as they can hold. And we then need a profession that can appreciate and learn from these stories. And that would be a valid epistemology, and a scientific approach, one that employs procedures and criteria that are appropriate to the materials we have to deal with, language and living.

Specifically, AC should take the lead in adding value to the traditional journal format through the use of on-line pictures and video. We should refrain from any self-denying ordinances with regard to the totality of the available evidence, and should not retreat behind a priori

disqualifications of particular forms. We must acknowledge the investment and involvement of the people we work with in the production of our research. As far as feasible, we should follow the slogan of the minorities, “nothing about us without us” and follow the example of Rubin et al (2001) in acknowledging the communicating subject as a research author.

One of the founding myths of modern science is Galileo’s challenge to his colleagues at the University of Padua to look at the moon through his telescope and verify for themselves the existence of mountains and plains on what Aristotle had described as a perfect sphere. Famously, they refused on the grounds that arguments established through logical deduction from revealed truths could not be rebutted by the mere appearance of phenomena that were in any case subject to varying interpretations and other explanations. It seems ironic that the name of science is now being invoked to justify ignoring observable phenomena in favour of written sources.

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