

The Autism National Committee

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The only autism advocacy organization dedicated to "Social Justice for All Citizens with Autism" through a shared vision and a commitment to positive approaches



AUTISM NATIONAL COMMITTEE (AutCom) POLICY and PRINCIPLES REGARDING FACILITATED COMMUNICATION

POLICY: It is the policy of the Autism National Committee that everyone has something to say and a right to say it. Facilitated Communication is one accepted and valid way in which individuals with autism can exercise their right to say what they have to say.

"It is hard enough to live in silence without anybody or anything making it harder or more uncomfortable."

- Sharisa Joy Kochmeister, Current AutCom President

PRINCIPLES:

- Everyone involved with people on the autism spectrum needs to be consistently open to and ready for opportunities to listen and to the obligation to explore any and all processes that enhance genuine communication and social connections between human beings.
- People with disabilities (including those on the autism spectrum) who do not communicate meaningfully through speech must have an available means of communication that allows their fullest participation in the world.
- All people have a right to communicate using their chosen method(s), and their communication must be respected by others. **To communicate is a right, not a privilege.**
- People who are denied access to whichever types of Augmentative and Alternative Communication (AAC) they require are denied their basic rights because communication is the basis of all other rights and the means by which those rights can be realized.
- Facilitated communication (FC) is one process to which those for whom this is already a viable form of AAC have an absolute right to access.
- Those who are not yet using Facilitated Communication and who are not speaking fluently have a right to be exposed to, and to receive, competent Facilitated Communication Training (FCT) in addition to being exposed to and receiving training in other specific processes and methods. These, as stated in the American Speech and Hearing Association (ASHA) Guidelines, must be part of a total communication approach that includes speech, signs or gestures, and/or access to low or high technology communication devices.
- The benefit of FCT in leading to FC as an acceptable and valid form of AAC has been established by (1) the number of individuals on the spectrum who are

typing independently today; (2) the studies in which at least some messages were passed correctly; and (3) practical applications when individuals' messages about pain, discomfort, choices, and other personal information have been successfully addressed.

- The primary goal of FCT is always for individuals to achieve independent typing. However, given the complexity of challenges faced by individuals, total independence in typing and in demonstrating literacy may not be possible at all times and for every single person.
- Children whose oral language is either absent or delayed for any reason must have access to any and all forms of communication (including AAC and FC) that are necessary and appropriate to enable them to communicate meaningfully in chronologically age-appropriate ways.
- Literacy is essential for an FC user to maximize skills learned through FCT and to become an independent typist. Therefore, literacy must be taught to all students regardless of the apparent severity of their disability. This is particularly true for students with autism spectrum disorders, whose complex movement, anxiety, connectivity, and sensory differences may preclude their demonstrating their abilities in conventional ways.
- At all times, the "least dangerous assumptions" must be made regarding each person's potential to learn. This is particularly true for people on the spectrum as well as those with other challenges involving communication. To be precise, cognitive potential should always be presumed to exist and a rigorous, systematic, and long-term commitment is required in order to unlock the doors of communication.
- FCT can help enable a person to overcome neuromotor, anxiety, communication, and sensory difficulties and to improve their pointing skills for other forms of communication, e.g., pictures and symbols, along with achieving literacy. However, literacy does not have to be demonstrated initially in order to attempt other methods of communication including, but not limited to, FC.
- Anyone attempting to introduce FC as a form of AAC must have at least the Beginner Competencies articulated in the Facilitated Communication Training Standards. Facilitators, as well as FC users, need to learn the range of technical skills essential to access and use FC reliably and validly with current and potential users. Those who provide training to facilitators, the facilitators themselves, and FC users require and must be provided on-going training, supervision, and support.
- Additionally, facilitators must adhere to strict standards in order to minimize facilitator influence (which AutCom acknowledges may occur) and to assure that all communication is generated and owned by the FC user. Intentionally guiding an FC user to a target is unacceptable under any and all circumstances.
- Funding must be available for FCT, facilitators, ongoing training, and the AAC device(s) each individual requires to communicate meaningfully.
- People with disabilities who use alternative forms of communication should be active and proactive at the local, state, national and global levels in shaping policies and practices of government agencies, professional organizations, and other entities that directly affect their lives. FC must be accepted in policy and practice as an equal choice among AAC opportunities.

- AutCom acknowledges that FC involves multiple forms of support provided by the facilitator, allows the FC user to communicate messages that differ in complexity and usefulness, and is highly individualized and based on the specific needs of the FC user. As such, using FC does not necessarily look the same from person to person. There is a wide diversity of supports and styles of pointing to targets involved and there is no single rote prescription of how to introduce or use FC. Instead, FCT and FC involve dynamic, active and long-term processes of identifying, implementing, and evaluating communication supports according to the Facilitated Communication Training Standards.
- AutCom reaffirms its groundbreaking 1992 statement in support of FC, and supports and endorses the TASH resolutions on communication and facilitated communication, the Breaking the Barriers project results, the work of the Facilitated Communication Institute at Syracuse University, and the information on FC reported in the Autism Society of America's journal in 2006 [c.f., "The Advocate", 3(1), 14-22].
- AutCom acknowledges that FC and many other forms of AAC may reveal competencies, feelings, and thoughts that were previously un-assumed and/or unexpressed. We also affirm that all individuals possess unique gifts and strengths whether or not they need some type of support to assist them in communicating those gifts and strengths.
- AutCom asserts unequivocally that there is nothing mystical, magical, miraculous or mythical about FCT or FC. Indeed, this is very difficult and challenging work for both facilitator and communicator.
- AutCom criticizes attempts to dismiss FC on the basis of studies that are poorly designed and/or whose results are incorrectly extrapolated to the entire population of FC users. In particular, we reject over-generalized claims that allege or imply that merely because FC is not valid for some people under some circumstances, FC is not valid for any person under any circumstances.
- AutCom additionally acknowledges that the existing body of research points to essential cautions in using AAC (including FC) with anyone who does not fluently and independently speak, sign, or write to communicate. Both genuine, user-authored communication as well as influence by others can occur in a given conversation involving any communicators, even those using oral language fluently.
- Facilitator influence is not an insurmountable obstacle to the responsible and dependable use of FC. Message-passing (in which the FC user communicates information that is not known to the facilitator) is a straightforward way of verifying FC's validity and can be assessed in everyday situations.
- AutCom always welcomes responsible research into AAC/FC using a variety of acceptable, valid, reliable research methodologies and standards. AutCom supports and endorses research that is currently underway as funded, for example, by the Nancy Lurie Marks Foundation. AutCom also notes that the American Psychological Association and other organizations have not precluded continued research into the use of FC.
- AutCom affirms that FC has already proven to be profoundly beneficial in the lives of many people by opening the door to reliable, trusted, and respected symbolic communication for the first time.

***"As for FC, it is a tool I use to get where I wish to go. Just as a voice is used by those who speak."* – Jenn Seybert**

Selected resources/references:

- Attwood, Tony, Ph.D., internationally known expert on Asperger Syndrome [c.f., foreword in Blackman, L. (2001) *Lucy's Story: Autism and Other Adventures*. JKP; Attwood, T. (1992), "Movement disorders and autism: a rationale for the use of facilitated communication". *Communication*, 26(3), pp. 27-29.]
- Crossley, Rosemary & Borthwick, Chris. (2002), "What Constitutes Evidence – Why the debate about facilitated communication is important for ISAAC." Paper written for the proceedings of the Seventh Biennial ISAAC Research Symposium, Odense, Denmark. http://www.fc2000.dk/Artikler/What_Constitutes_Evidence.pdf
- Cable News Network (2005). CNN Presents: Facilitated Communication Studies. <http://www.cnn.com/CNN/Programs/presents/shows/autism.world/fc/studies.html>
- Kasa-Hendrickson, Christi, Ph.D., educator [c.f., Kasa-Hendrickson, C. (2006). "Typing to Communicate: Understanding Facilitated Communication". *The Advocate*, 3(1), 14-22.]
- Damasio, Antonio, M.D., internationally known physician and neuroscientist.
- Donnellan, Anne, Ph.D., internationally known educator and autism expert. [c.f., with Martha Leary, CCC-SLP. Reg CASLO (1995): "Movement differences and diversity in autism/mental retardation". Madison, WI: DRI Press.]
- Facilitated Communication Institute at Syracuse University (2000). *Facilitated Communication Training Standards*. Syracuse, NY: author. <http://www.inclusioninstitutes.org/index.cfm?catID=8>
- Greenspan, Stanley, M.D., pediatric psychiatrist. [c.f., Lecture 8: Review of the Model, Basic Course on the DIR®/Floortime™ Training on-line course (2008)].
- Maurer, Ralph, M.D., psychiatrist. (Collected works).
- Pratt, Jacob (2008). "Teaching Your Support Staff How to Understand Your Autism Using the MACS Approach". Rocky Hill, CT: ASDI/NE.
- Shevin, Mayer & Schubert, Annegret. "Message-Passing: Part of the Journey to Empowered Communication". <http://www.inclusioninstitutes.org/index.cfm?catID=30&articleID=53>
- Kochmeister, Sharisa Joy, B.A. (dual major), AutCom President & FC user/ independent typist. <http://sharisa-kochmeister.blogspot.com>; http://blog.360.yahoo.com/blog-1veq9NMic6dhDvPf_YYFDh8M;_ylt=Aq7RhI69A5CUWAV9eU3IJ6.kAOJ3
- Weiss, Michael, Ph.D., behaviorist [c.f., Weiss, M., Wagner, S.H., & Bauman, M.L. (1996). "A validated case study of facilitated communication". *Mental Retardation*, 34, 220-230; "Evidence Based Behavior Management," www.revolutionhealth.com/blogs/michaelweissphd]

AutCom invites anyone with questions about this policy and its principles to contact the Autism National Committee using the website at:

<http://www.autcom.org/contact.html>

or by using regular mail addressed to:

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